

Institute of Education, University of London
PSYCHOLOGY AND HUMAN DEVELOPMENT

An exploration of individual patterns of development of six pre-school children who have recently received a diagnosis of autism and the response of their parents to differing experiences of early support and intervention

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A thesis submitted in partial fulfilment of the requirements of the Institute of Education, University of London, for the Doctorate in Professional Educational, Child and Adolescent Psychology.

by

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I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own.

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ABSTRACT

This study explores the individual patterns of development in aspects of cognitive functioning, communication and language skills, social interaction and adaptive behaviour of six pre-school children following a diagnosis of autism. The perceptions of the parents were gained in order to explore their experiences of the impacts of a diagnosis of autism on their families. Additionally, the experiences of three of the children's parents who took part in the EarlyBird Programme and their perceptions of its effects on the child and family were explored as part of the study. These views were compared to two of the three children's parents who did not take part in the EarlyBird Programme.

The study adopted a multiple case study design within a mixed methodology framework. The research methods incorporated semi-structured interviews with five of the six parents (one parent did not give consent to be interviewed), three standardised assessment questionnaires (Vineland Adaptive Behaviour Scales-2, The Strengths and Difficulties Questionnaire and The Gilliam Autism Rating Scales-2) of all six children and psychometric assessments (The British Ability Scales-II) of five of the six children (one child refused to cooperate with the researcher) as well as informal observations of the children's behaviour. Data were gathered at two time points, approximately six months apart.

Five of the six children in the study showed greater improvement than expected in some aspects of their development over the time period of the study. However, the significant individual and family differences and the limited sample size means that developments in the children cannot be attributed to any one factor. Participation in the EarlyBird Programme indicated reduced levels of maternal stress in the EarlyBird group of parents, although this reduction was reported verbally and was not objectively

measured. The positive impact of support, both from other parents and professionals within the EarlyBird Programme, as well as increased support from fathers, as encouraged by the programme, was a major theme which emerged from the interviews with parents. It could be suggested that providing informal support to this population of parents in the period immediately following diagnosis, as an alternative to a formal programme, might yield similar results.

CHAPTER 1

INTRODUCTION

Autism has life-long consequences with a range of impacts on health, economic well-being, social integration and quality of life for individuals with the disorder, and also on their families, and potentially on the rest of society. As well as bearing the practical burdens and psychological stresses of having a child with autism, and facing family disruption and in some cases even breakdown, (Knapp, Romeo & Beecham, 2007) many parents and carers also experience disruption in their employment, constraints in career progression and consequent losses in earnings (Jarbrink, Fombonne, & Knapp, 2003).

According to recent research commissioned by the Foundation for People with Learning Disabilities (2007), and Knapp, Romeo and Beecham (2009) the annual cost of autism to the UK is just under £28 billion, with children costing £2.7 billion and adults £25 billion. These figures illustrate the real cost of autism and, as McCulloch (2007), head of the foundation, stated in a recent press release, give serious weight to the argument that more resources are needed to intervene early and effectively in the lives of those who are affected by the condition. He went on to say that he believed that early intervention would help individuals with autism and their families experience a *“better quality of life and reduce the high costs incurred in later years, saving public money.”*

Parents provide the main developmental context for their child, yet it has been highlighted that they often feel ignored by professionals involved in diagnosis and treatment and express dissatisfaction with the situation where there is a gap between diagnosis and educational advice and treatment for their child (Howlin & Moore, 1997).

Parents of children with autism may feel inadequate and high levels of stress can be experienced as they are trying to understand and cope with their child (Shields & Simpson, 2004). Bristol, Gallagher, & Holt (1993) identified some factors that appear to contribute to the stresses associated with living with a child with autism. The social isolation and distress that can result from a child with any disability has been well documented (Bristol et al. 1993). In addition the social, communication and behavioural manifestations of autism often produce a lack of understanding from the general public and the parents' handling of the child may be criticised, increasing the levels of stress for these parents. High levels of parental stress can also be associated with factors outside the family, particularly the lack of help and support in the period immediately following a diagnosis, as well as the factors relating to the child (Kasari & Sigman, 1997).

In the last decade great gains have been made in understanding the structural and behavioural nature of autism and research has shown some positive outcomes in young children receiving early intervention services. Findings reveal that most children with autism benefit from early intensive behavioural intervention, but it remains unclear if there is a threshold for the number of hours per week, the length of treatment, the age at intake, and/or the characteristics of the child that affects the outcomes (Howlin, 1997; Mesibov, 1997). There has been an increase in home-based intervention programmes that aim to capitalise on working in the child's natural environment over recent years, however, there is a risk that home-based programmes may become intrusive and expensive, thereby increasing the stress on families (Shields, 2001). Some families can cope with the long term commitment of highly intensive programmes; others will lack the time, energy or financial resources required. Evaluation of parent training programmes suggests that they can be a cost effective way to support children with autism and their families (Birkin, Anderson, Moore & Seymour, 2004), although at present there is scant evidence on these programmes, their outcomes for the child, the family and their cost effectiveness.

There is little research documenting the developmental trajectories of this group of children. However, it has been recognised that children with autism do not follow 'typical' developmental trajectories, even more so within the first five years, where unusual patterns of development have been documented (Munson, J, Faja, S, Meltzoff, A, Abbott, R & Dawson, G, 2008). Due to such unusual patterns of development, in what has already been recognised as such a heterogeneous group, drawing conclusions about the effectiveness of intervention programmes is limited. This therefore acts as a significant challenge for any researchers in this field and also acts as a challenge to the evidence base in this area. Development cannot be attributed to a single programme, but rather it may be due to individual factors that need to be taken into account.

However, it is proposed that the current study will provide a distinct contribution by exploring the individual patterns of development of six pre-school children and the experiences of their families in the period immediately following a diagnosis of autism. Their parent's views will be gathered in order to explore their experiences of the impact of a diagnosis of autism on the family, their perceptions of their child's development over the course of the study, and factors that they feel have contributed to any reported developmental gains during the time period of the study. All six children's parents have been offered the opportunity to take part in the EarlyBird Programme. However, only three have decided to sign up to take part in the 13-week programme, and three have not. The study, therefore also aims to explore the perceptions of those parents who take part in the EarlyBird Programme about its effectiveness. The parents who do not take part in the programme will be interviewed about their reasons for not taking part and the factors that challenged their access to the programme. This will provide the opportunity to explore the parent's views on alternative forms of parental support that they feel could be offered in the period immediately following a diagnosis of autism.

Due to the high costs involved in early intervention programmes, and the drain on Local Authority resources, an exploration of the experiences of families whose children have recently received a diagnosis of autism will be of benefit to the Local Authority as well as the children and families in question. Gaining their views on alternative forms of support and/or intervention that could be offered in the local communities where the study takes place could help the Local Authority to provide appropriate support services to vulnerable families that may otherwise fall through the net.

Additionally, the current research aims to keep within the National Development & Research Themes (D&R) in Educational Psychology and to advance the knowledge base of the profession, in particular, 'Identifying Effective Intervention Strategies for Children and Young People with Autistic Spectrum Disorders.'

The research will be presented in the following five chapters. Chapter 2 will present a review of the relevant research literature relating to autism and early intervention. An outline of the methodology will be presented in Chapter 3, which will detail the design, participant profiles, measures used and the procedure that was followed. Chapter 4 will present the results of the study. A discussion of these results, drawing on pertinent literature, and an outline of the implications of these results for practice and future research will be presented in Chapter 5 before concluding the study in Chapter 6.

CHAPTER 2

LITERATURE REVIEW

The following chapter will provide an overview of the current literature concerning autism, its prevalence, early identification and intervention. The literature on autism has increased significantly over the past decade; therefore an attempt will be made to present a critical analysis of the key research in the field, whilst highlighting the need for the current study.

2.1 AUTISM

2.1.1 General Overview

Autism is a developmental disability that typically appears during the first three years of life and is almost always chronic (Smith & Lovaas, 1998). Throughout the past five decades there has been significant progress in validating Kanner's (1943) concept of autism. Similar to his original description, autism continues to be identified as a behavioural disorder, although the view on aetiology of the disorder has changed. Cohen and Volkmar (1997) aptly addressed the complexity inherent in this disorder, where they state that virtually every type of theory relating to child development has been applied, in order to attempt to understand the inscrutable impairments and competencies of individuals with autism. Currently, autism is believed to be the result of a neurological disorder that affects the normal functioning of the brain (CDC, 2007; Freeman, 1997), affecting the individual's ability to interact with the surrounding world.

Autism is viewed as a spectrum disorder with varying degrees of behavioural presentation, where different children diagnosed with autism can present with a wide range of abilities and impairments, including stereotypical and challenging behaviours,

cognitive ability, communication and social skills. Other disorders included in the spectrum are pervasive developmental disorder – not otherwise specified (PDD-NOS) and Asperger's Syndrome (Freeman, 1997; Schoen, 2003). All have similar symptoms, but they differ in terms of when the symptoms begin, how quickly they appear, and how severe the symptoms are (CDC, 2007) (See Appendix 1 for DSM-IV diagnostic criteria). Although prognoses are diverse, it is viewed as a chronic disability that results in lifelong impairment for most individuals (Freeman, 1997).

The main impairments caused by autism are in the areas of social interaction, communication and restrictive repetitive and stereotyped patterns of behaviours, interests and activities (DSM-IV, 1994), often termed 'The Triad of Impairments' (Wing, 1996). More recently the term 'Tetrad of Impairments' has been used by some professionals in order to highlight 'sensory impairment' amongst the difficulties that people with autism experience. This term is not currently used within academic publications and it appears that the majority of researchers still refer to the 'Triad' when describing the difficulties associated with the condition. The impact of these difficulties on a child with autism can be far reaching, affecting their school lives, family and society as a whole. However, it must be highlighted at this stage that much of the research on autism focuses on deficits and difficulties, rather than on difference, which is not necessarily the world view that the researcher conducting this study adopts. The researcher also subscribes to models of autism and disability such as the 'Social Model' (Oliver, 1990) and 'The Affirmation Model' (Swain & French, 2000). The focus of these models is not on the 'impairments' in autism, but rather on the individual's development of their personal identity as shaped by their experiences of having autism, and their personal acceptance of the condition. Unfortunately, it is beyond the scope of this study to discuss or compare the different models that help us to understand autism and its effects on the individual in more detail.

For the purposes of this study, the documented effects of difficulties with social interaction, communication and imagination will be discussed in more detail later on in this chapter.

2.1.2 Increased Prevalence

A number of studies, using various diagnostic criteria, have attempted to determine how many children have autism at any one time in a population of a given size. Wing and Potter (2002) state that there are a number of problems that arise when attempting to conduct such epidemiological studies, including difficulties with diagnosis, study designs and terminology. There are no medical tests to determine whether a person has autism, and therefore, diagnosis is made on the basis of behavioural descriptions. This leads to subjectivity as professionals differ in the way that they apply criteria for diagnosis, as well as how they record case notes and centralised data collections. Diagnostic terms tend to be used in different ways, and often there is an overlap among subgroups named in the ICD-10 and DSM-IV with many individuals fitting more than one diagnosis within the spectrum.

Autism was once considered a rare condition affecting as few as 3 to 4 individuals per 10,000 (Lotter, 1966), however more recent reviews (Fombonne, 1997) estimate the incidence of autism as varying from 0.7 to 15.5 per 10,000, with 5 cases of classic autism per 10,000. Chakrabarti and Fombonne (2001), in a more recent UK study, found that the prevalence rate for an 'autistic disorder' was 16.8 per 10,000, and 62 per 10,000 for Pervasive Developmental Disorders (PDDs). A follow up study, conducted in 2005, found an increased rate of 22 per 10,000 for the same population of 10,900 children between the ages of 4-7 for 'autistic disorders' and 59 per 10,000 for PDDs (Chakrabarti & Fombonne, 2005). Baird, Simonoff, Pickles et al. (2006) found that the prevalence of childhood autism was 38.9 per 10,000, and that of other spectrum disorders was 77.2 per 10,000, making the total prevalence of all Autistic Spectrum

Disorders 116.1 per 10 000 in the population studied. They concluded that the prevalence of autism and related disorders was substantially greater than was previously recognised. Their study also highlighted that services in health, education and social care need to recognise that 1% of the child population have some form of autism.

Prevalence figures for presentation of autism in boys and girls have consistently shown that autism is more common in boys, especially in more able individuals (Ehlers & Gillberg, 1993). The literature suggests a ratio of 4:1 for classic autism and 9:1 for Asperger's syndrome (Bryna, 2003). Recently, Gillberg (2005) has speculated that there may be an under-diagnosis of more able females with Asperger's syndrome, as their presentation of difficulties may be different in nature from their male counterparts. This theory is supported by Baron-Cohen (2002) who hypothesised that systematising and empathising mental domains are associated by gender, and that females with Asperger's Syndrome are more likely to be able to relate to others. Therefore their social difficulties may be less pronounced. This would impact on the prevalence of diagnosis in females.

The reasons for the increased prevalence are continuously being debated. Fombonne (2005) concluded that most of the increase is due to improved identification and the changes in diagnostic concepts and criteria. In the United States, Mandell and Palmer (2005) concluded that the higher rates of diagnosis were due to the higher levels of educational and health spending, meaning that less children were 'falling through the net.' McConkey, Kelly, & Cassidy (2007) speculate that the increase could be due to better trained educationalists, better access to paediatricians and school based health services, as well as the increased recognition of autism with the professional domain, as well as in the public. Baird, et al. (2006) question whether the increase is due to better ascertainment and broadening diagnostic criteria, or merely increased incidence. Environmental causes of the rise in prevalence of autism have not been confirmed by

independent scientific investigation, whereas there is strong evidence that complex genetic factors play a major role in aetiology (Bailey, Palferman, Heavey & Le Couteur, 1998; Folstein & Santangelo, 2000, Ronald, Happe, Price, Baron-Cohen, & Plomin, 2006). Twin studies such as the Bailey, Le Couteur, Gottesman, Simonoff, Yuzda & Rutter (1995) study have highlighted the genetic determination of autism, where it was found that 92% of monozygotic pairs had some cognitive or social difficulties associated with the condition. Wing and Potter (2002) state that evidence suggests that the majority, if not all, of the reported rise in incidence and prevalence is due to changes in diagnostic criteria and increasing awareness and recognition of autism.

Charman and Baird (2002) in a review of the diagnosis of pre-school children with autism outline a number of factors that may have contributed to the increase. Firstly, there is an increasing recognition that individuals with average cognitive ability may have an Autistic Spectrum Disorder (Gillberg & Wing, 1999). Secondly, the identification of autism in individuals with co morbid disorders has dramatically increased. This includes Down's syndrome (Howlin, Wing, & Gould, 1995), cerebral palsy (Fombonne, du Mazaubrun, Cans, & Grandjean, 1997; Nordin & Gillberg, 1996), Tourette syndrome (Baron-Cohen, Scahill, Izaguirre, Hornsey, & Robertson, 1999), Turner syndrome (Creswell & Skuse, 1999), tuberous sclerosis (Harison & Bolton, 1997) and individuals with hearing and visual impairments (Cass, 1998; Nordin & Gillberg, 1996; Roberts & Hindley, 1999). It can also be hypothesised that the early identification of autism, a recent advance, may have contributed to the increase in prevalence, as many children are now being identified within the pre-school period (Baird, Charman & Cox, 2001; Filipek, Accardo, Baranek, Cook, Dawson, Gordon, et al., 1999; Rogers, 2001; Howlin & Asgharian, 1999).

There does not appear to be an answer to the question of increased prevalence, although the researcher believes that awareness of the disorder has had a significant impact on the perceived increase in prevalence. Within the current context, many

teachers, Special Needs Coordinators and Educational Psychologists are aware of the impairments and behaviours that would place a child at risk of receiving a diagnosis of autism. Additionally, children in the secondary school years are increasingly being diagnosed as having some form of autism, although the validity of the diagnostic measures being used for this population of children is questionable. Questions concerning increased prevalence may never be answered. It is therefore an issue that will continue to be discussed at length with much speculation as it is virtually impossible to answer the question using objective scientific evidence. The question of increased prevalence is not the focus of the study, although the researcher is aware that for those charged with providing special provision for children with autism in local authorities, it is. On the other hand, this study focuses on questions around which interventions and support work best for this group of children, as by intervening appropriately the researcher believes that the quality of life for children with the disorder, and their families, can be significantly improved.

2.1.3 Early identification

The ability to recognise and diagnose the disorder at a very early age has been highlighted as one of the most exciting developments in the field of autism in recent years (Dawson & Osterling, 1997; Matson, Wilkins & Gonzalez, 2008). A number of studies (Ornitz, Guthrie, & Farley, 1977; Dahlgren & Gillberg, 1989; Gillberg, 1990; Baron-Cohen, 1992; Baron-Cohen, 1996) confirm that early recognition of autism and its discrimination from other developmental problems requires attention to a number of subtle indicators, including a delay in smiling, failure to follow a parent's gaze, and failure to respond to his or her name or a parent's pointing gesture by the age of 10 to 12 months. Parents are usually the first to be aware that something is wrong with their child, as it is not easy to detect autism in routine medical examinations, and indeed most cases are picked up by paediatricians, psychologists or teachers who possess knowledge of the important social features of autism.

Evidence that signs of autism are apparent within the first 2 years of life comes from several sources, including parent's retrospective reports (Gillberg, 1990; Charman, 2000), home videos (Baranek, 1999), and case studies of children later diagnosed with autism (Dawson, 2002). Evidence also comes from the systematic study of 41 high risk infants, all with a sibling diagnosed as having autism, in which four children exhibited distinct autistic signs at 18 months of age (Baron-Cohen, Allen & Gillberg 1992).

The first signs of autism are usually observed by three years of age, although due to increased knowledge of the disorder, many parents will first start noticing difficulties in these areas (a delay in smiling, failure to follow a parent's gaze, and failure to respond to his or her name or a parent's pointing gesture) between 15 and 18 months of age (Ozand, Alodaib, Merza, & Al Harbi, 2003). Research has demonstrated that up to 55% of children on the autistic spectrum show some symptoms before the age of one year, up to 88% before the age of two (Gray & Tonge, 2001), and 93% before the age of three (Matson et al., 2008). However, recent evidence indicates that most children in the United States are not diagnosed prior to age 4 years, typically at least 2 years after parents first seek professional advice because they are concerned about their child's development (Wiggins, Baio, & Rice, 2006). In the United Kingdom the average age of diagnosis is 5 or 6 years of age (Matson et al., 2008; Filipek et al., 1999), although the researcher is aware that the age of diagnosis varies considerably across the UK, depending on where the child lives. It has been reported (Dawson & Osterling, 1997; Matson & Minshawi, 2006) that most children are seen by at least three professionals, and parents experience significant distress and frustration before a diagnosis is received. The long delay between parents' initial concerns and eventual diagnosis also postpones appropriate intervention, which, coupled with evidence of its effectiveness (Dawson & Osterling, 1997; Matson & Minshawi, 2006), leaves parents with the sense that precious time has been lost. Perhaps it is the frustration that is caused by this delay in diagnosis that encourages parents to join lobby groups. These groups may

help them feel that they are doing the best they can to secure appropriate support for their child, and more importantly that their 'expertise' as parents is being respected and they are being listened to.

Researchers and practitioners appear to be emphasising the importance of early identification, highlighting the earlier the better (Swinkles, Dietz, van Daalen, Kerkhof, van Engeland & Buitelaar, 2006). However, the arguments put forth are largely unsubstantiated by data. Researchers need to establish if early identification, for example, results in better family support and improved outcomes for the child. Additionally, as Matson et al. (2008) point out, there are a number of areas which need considerable experimental development and questions such as, '*what is family support and what are the best empirical methods to provide it?*' (pg. 56) need to be answered.

2.2 IMPACT OF AUTISM

Difficulties with social interaction, communication and behaviour have an impact on the daily functioning and coping skills of a child with autism. Unfortunately, the impact is not only on the child, but the impacts on the adults and other children working and living with the child are also far reaching. Within a school environment a child with autism often needs to be supported through the school day by an additional adult, due to difficulties with social interaction and communication. They often also find it extremely difficult to cope with any changes in their typical routine, increased noise and unpredictability (Knapp et al., 2007). The implications on the family will be especially large when the individual has additional needs, such as a moderate or severe learning difficulty. The consequences of autism can be seen in a number of domains, including family and other relationships, leisure activities, standards of living, social and personal functioning and the individual and their family's quality of life. These consequences

tend to persist through childhood into adulthood and impact on the health, economic and social well-being of individuals, their families and society as a whole.

2.2.1 Impact of the Triad of Impairments

2.2.1.1 Social interaction

Typically, individuals with autism exhibit difficulties in the area of social skills, which affects their ability to interact with others. Avoidance of eye contact or a preference to look at objects and people out of the corner of their eyes (Schoen, 2003; Smith & Lovaas, 1998) is one markedly significant aspect of autism. Social interaction consists of three basic elements, these include; social intake – noticing and understanding other people’s speech, vocal inflection, body language, eye contact, and even cultural behaviours; internal process – interpreting what others communicate to you, as well as recognising and managing your own emotions and reactions, and social output – how a person communicates with and reacts to others, through speech, gestures, and body language (Christophersen & Mortweet, 2003). It is therefore understandable how difficulties in these areas have significant implications for a child with autism in the school and home environments. They may miss social cues such as facial expressions, body language and gestures and have difficulty understanding what other people are thinking and feeling, and often find it difficult to express their own feelings appropriately (Schoen, 2003). In addition, children with autism may also have difficulty with imaginative play and interacting with their peers (Smith & Lovaas, 1998), and often have a misunderstanding about the use of personal space. Within an educational setting the inability to understand and make sense of social cues not only impacts on the child’s relationships with his peers, but additionally reduces the amount of non-verbal communication that can be understood by the child when taking part in day to day learning activities.

2.2.1.2 Communication

Difficulties with communication has been highlighted as another significant area of impairment. This includes the use of spoken language, which affects a high percentage of individuals with autism. Some individuals may be able to speak, but do not use language functionally and may only echo what others say (echolalia) or repeat favourite phrases that they have heard on the radio or television (Siegel, 2003). It is estimated that the proportion of children with autism who do not develop speech ranges from 19% to 59% (Fombonne, 1999), and a significant number of individuals with autism have limited functional spoken language (National Research Council, 2001). Some individuals may talk only about preferred items or activities and have no interest in what other people have to say. Difficulty with understanding jokes, idioms, or maintaining an appropriate distance between themselves and others during conversation has also been highlighted (Frith, 2003; Happe & Frith, 2006).

Difficulties with communication can often lead to frustration, which in turn may impact significantly on the child's behaviour. It has been suggested that poor expressive language and social interaction skills are associated with the development of challenging behaviour in individuals with autism (Murphy, Beadle-Brown, Wing, Gould, Shah, & Holmes, 2005), which has been highlighted as one of the most difficult aspects of autism for parents and the school to cope with (Clements & Zarkowska 2000; Cumine & Dunlop, 2009). It has been suggested that there is a relationship between child behaviour problems, parental stress and parenting behaviour (Hastings, 2002). Whether it is an inability to process the verbal and non-verbal information given, or an inability on the individual with autism's part to verbalise their needs or frustrations, both play an important part in the resulting challenging behaviour displayed. The impacts of communication difficulties can therefore be far reaching for a child with autism. Difficulties with expressive and receptive language do not only lead to frustration for the

child, but also impact on their ability to follow a school curriculum without significant adult support. Their ability to make and maintain friendships, which is further exacerbated by their difficulties with social interaction, is therefore also limited.

2.2.1.3 Behaviour

Finally, individuals with autism also exhibit repetitive behaviours and appear to have an intense need for routine and structure in their lives (NRC, 2001; Trevarthen, 2001). They may prefer to engage in stereotypical behaviours such as spinning the wheels on a toy car instead of pushing it across the ground. They may also engage in behaviours such as humming, rocking, and flapping their hands in front of their face; behaviours which have also been described as 'stimulatory,' as it is hypothesised that the individual with autism is seeking sensory arousal (Bogdashina, 2003).

As already mentioned, many children with autism also engage in various forms of challenging behaviours (Dawson & Osterling, 1997; Simpson & Myles, 1998), such as absconding, self-injury, disruption and aggression. The relationship between child behaviour problems and carer stress has been supported by research in children with developmental delay (Hastings, 2002) and in children with autism (Lecavalier, Leone, & Wiltz, 2006). A diagnosis of autism, severe learning difficulties (SLD) and deficits in receptive and/or expressive communication have been identified as risk markers associated with challenging behaviour (McClintock, Hall & Oliver, 2003; Holden & Gitlesen, 2006). Additionally, the presence of challenging behaviour in individuals with autism is associated with lower personal well-being in their caregivers (Hastings, 2002) and exclusion from mainstream educational settings, as evidenced by a national survey by the National Autistic Society in 2001, which found that one in five children, who reported their experiences of mainstream education, had been excluded from school at some point (Barnard, Prior & Potter, 2000). Challenging behaviour appears, therefore, to have a significant impact on the individual, the family and the child's education.

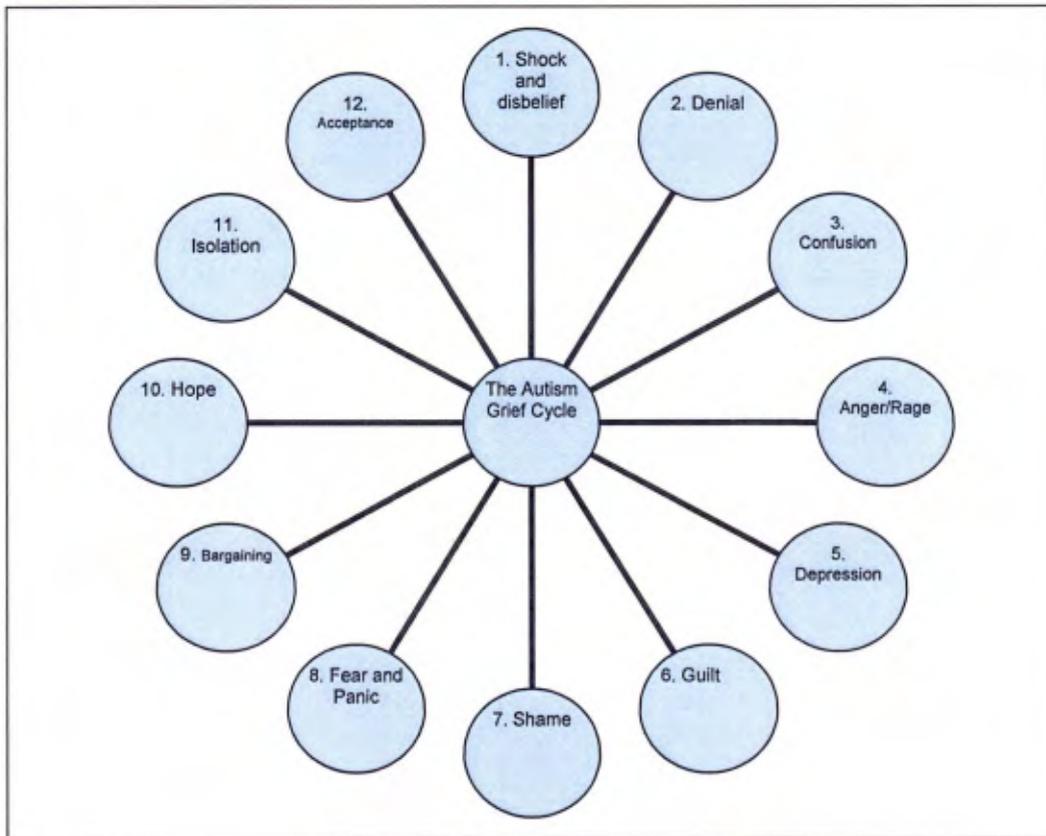
Specifically, the ability of educational settings to successfully include this group of students into mainstream education becomes more limited where levels of challenging behaviour are high.

2.2.2 Impact on the family

2.2.2.1 Grief reaction associated with diagnosis

When a child is diagnosed with autism parents experience a range of feelings, although the reaction to a diagnosis of autism varies very much from family to family. This reaction has most commonly been described as a 'grief' reaction, due to the intense feelings of loss that parents have reported. Additionally, Nissenbaum, Tollefson and Reese (2002) reported that parents can also experience a sense of relief that their suspicions have finally been validated. They no longer feel that the problems they face are due to their lack of parenting skills, and they have an explanation for themselves and others as to why their child exhibits unusual behaviours. Recently researchers have reported that parents of children with autism appear to follow a cycle of grief that is unique to this population (Sicile-Kira, 2004), which has been labelled as the 'Autism Grief Cycle.' Parents pass through a number of stages when their child is diagnosed with autism, stages which can also re-occur at different times throughout the child's life as different events (e.g., birthdays, holidays, endless care-taking) trigger grief reactions that have already occurred (Worthington, 1994). The stages of the 'Autism Grief Cycle' have been diagrammatically represented in Figure 1 by the researcher for ease of reference. Not all parents pass through all the stages and parents can pass through more than one stage at a time. This cycle is similar to that which was described by Kubler-Ross (1969), as far back as 1969, when studying grief reactions to bereavement and loss.

Figure 1: The 'Autism Grief Cycle' – Adapted from Sicile-Kira, 2004



In their study, Nissenbaum et al. (2002) found that the reaction to a loss has patterns of shock, denial, coping, depression, and acceptance in adults. Guilty feelings, depression, and anxiety were part of this process and it took more than a couple of months to reach the supportive and adjustment phase in some parents. Additionally, parents are distraught by the loss of lifestyle that they imagined for themselves and their family (Avdi, Griffin, & Brough, 2000), and these feelings of anguish can cause an additional build up of stress. Some parents in the study did not believe the diagnosis and some even became angry or questioned the professional's ability. Many were worried as to how other close relatives and friends would react to the diagnosis, although where parents suspected that their child had autism there was a decrease in the likelihood of shock. Diagnostic confusions, behavioural and health problems, and feelings of loneliness in parents also add to the burden and increase levels of stress in this population of parents. The increase in the severity of the disability results in a more dependent child, more responsibility for the parents, and therefore more anxiety in the

parents. Futagi and Yamamoto (2002) found that the earlier a child was diagnosed, the sooner the parents came to accept the diagnosis.

The results that were described in both the Nissenbaum et al. (2002) and Futagi and Yamamoto (2002) studies are what would be expected in this population. The researcher believes that this may be due to the child with autism appearing 'normal' for the first few years of life, due to the behaviours that lead to a diagnosis only becoming apparent in most children closer to two years of age. Parents by this stage would have already 'envisioned' a life for their 'normal' child and the sooner that a diagnosis can be made, the sooner the grieving process can begin, which leads to quicker acceptance of the child by the parents, which in turns leads to them seeking appropriate support for themselves and their child.

2.2.2.2 Resolution of Diagnosis

In addition to examining parental reactions to diagnosis, investigators have studied the degree to which parents of children with disabilities have resolved their feelings associated with the diagnosis, a concept labelled 'resolution of diagnosis' by Pianta and Marvin (1993). According to Pianta and Marvin, successful resolution involves accepting the diagnosis, incorporating the diagnosis into one's reality and resisting self-blame. There is a body of literature concerning parental resolution associated with other disorders, but unfortunately not with autism. 'Resolution of diagnosis' has been associated with improved parent-child interaction and attachment status, as according to Pianta and Marvin, parents who have not resolved their grief and other distressing emotions and cognitions that emerged as a reaction to their child's diagnosis find it harder to be attuned and responsive to their child's cues. Lack of resolution can interfere with sensitive parenting, which is known to be associated with secure child attachment status (Stams, Juffer, & Van Ijzendoorn, 2002). Given the literature illuminating the difficulty associated with learning of a child's diagnosis of autism and

some evidence that maternal interaction may impact on a child's developmental course, it is critical to explore interventions that encourage maternal support, which may lead to a decrease in the time it takes for the mother to accept her child's diagnosis and therefore increase positive interaction. It is logical to assume, therefore, that acceptance of a diagnosis and suitable maternal support would ultimately have a positive impact on the child's development.

2.2.2.3 Parental Stress

Parenting stress and parenting burden are associated with high levels of psychological distress and depression (Dumas, Wolf, Fisman, & Culligan, 1991; Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008; Tomanik, 2004). It is therefore not surprising that parents of children with autism are seen to be at a high risk of developing mental health problems (Piven & Palmer, 1999; Ryde-Brant, 1990). Caring for a child with autism is demanding and presents significant challenges to parents, particularly mothers, who are often the primary caregivers. Family stresses related to the care of children with autism have been shown to be significantly greater than the stresses experienced in the care of children with other developmental disorders (Sanders & Morgan 1997; Bromley, Hare, Davison & Emerson, 2004). Several studies have reported severity of autistic symptomology to be positively associated with parental stress (Freeman, Perry & Factor, 1991; Hastings & Johnson, 2001), with behaviour problems being highlighted. Behaviour problems are frequently reported in young people with autism, yet the relationship between this and parental stress has received little attention in this population. The challenges in communication and learning, due to issues related to emotional expression and language impairments; the extra care giving needs, due to the children's lack of self-care skills and ongoing dependency needs and the ongoing need to advocate on behalf of the child, particularly with schools and mental health and social agencies, has also been

highlighted as particularly stressful (Dumas et al., 1991; Tomanik, 2004, Little & Clark, 2006).

Parents of children with autism face challenges that are unique to this group of individuals, which impact on their psychological adjustment. Some of the challenges are presented by the intervention that parents opt into, for example, early intensive programmes, which are time consuming and expensive. Many parents stop working in order to coordinate their child's treatment, and the families are then faced with additional financial burdens during a stressful time. Furthermore, parents are often feeling stressed due to the challenges of autism, including their child's uneven cognitive development, problem behaviours and absence of social competencies (Davis and Carter, 2008). It is not surprising, therefore, that parents of children with autism experience a higher level of stress and elevated depressive symptoms than do parents of healthy, physically ill, or developmentally delayed children who do not have autism (Baker-Ericzen, Stahmer, & Burns, 2007; Eisenhower, Baker, & Blacher, 2005).

Clearly, interventions that also help mothers to reduce parenting stress are important. However, most interventions focus on training parents to intervene with their child and there is little evidence of the benefits of these programmes on parental and family stress. Less attention has focussed on the needs of parents, as little is known about the specific sources of stress related to parenting children with autism. Studies of parent stress either assume stress from the diagnosis, or measure stress globally without reporting the specific sources of stress. Knowing more about the experiences of parents who have children with autism has been highlighted by Phetrasuwan & Miles (2009) as being important when designing more specific interventions focussed on reducing parent stress.

2.2.2.4 Siblings

Research into the psychosocial adjustment of siblings of children with autism has had mixed results. Studies report decreased levels of social competence, (Rodrigue, Geffken, & Morgan, 1993; Bågenholm & Gillberg, 1991) high levels of loneliness and problems with peers in siblings of children with autism. Kaminsky and Dewey (2002), however, found low levels of loneliness in the siblings of children with autism but also found loneliness to be related to a lack of social support from friends. A lower level of social support from classmates was also significantly correlated with a higher level of academic problems in siblings of children with autism. As Howlin and Yates (1990) describes, there is some evidence that having a sibling with autism is associated with positive self-concept, interpersonal and care-taking skills. Also, and especially for sisters who assume a greater mothering role than do brothers, this extra responsibility does not appear to contribute to poorer adjustment. Higher parental expectations, however, can be a problem for the child with autism's typically developing brother/s (Miller, 2001).

A review of other research by Miller (2001) revealed that factors such as birth order, gender of siblings, severity of disability and parental behaviour will affect the sibling relationship. It was also found that the greater the number of children in the family, the better the psychosocial adjustment of siblings of children with autism. Possible explanations for this include better adjustment in larger families and the fact that additional siblings provide an important source of social support and the burden is shared. No gender differences were found in any of these analyses, although there did appear to be differences according to the age of the siblings. In cases where the sibling of a young child with disabilities is a preschooler, the parents themselves are likely to be in the initial stages of adjustment to the reality of the child's disabilities, resulting in fewer quality interactions with the preschooler than usual (Lobato, 1985). Consequently, these children may be particularly vulnerable to feelings of confusion and isolation.

Rivers and Stoneman (2003) stress the importance of considering family context as a contributor to the quality of the sibling relationship. They found that families with a child with autism, who were experiencing high marital stress and who sought greater support from formal sources external to the family, had siblings who reported a higher level of negative sibling behaviours than families who sought low levels of formal support. This is another interesting finding, and one that should be explored further when designing intervention programmes for children with autism. The question of, 'what support is better' thus arises in response to the impact that certain types of support has on the family as a whole. Should intervention programmes focus solely on the development of the child with autism, or should the family context be taken into account? Perhaps this is a question that can be answered as research in this area continues to develop.

2.2.3 Society

Autism impacts on society due to the economic costs per individual with the disorder over their lifetime. The most recent reviews of the economic costs of autism in the UK (Knapp et al., 2007 & 2009) found that the average lifetime costs for an individual with 'high-functioning' autism was found to be £3.1 million, and £4.6 million for an individual with 'low-functioning' autism (Knapp et al., 2007 & 2009). These estimates span all areas of public sector expenditure, including education and housing, as well as the high cost of autism to families in terms of out-of-pocket expenses, lost income and lost employment.

The combined national costs of supporting children with autism are estimated to be £2.7 billion. Of this total £1.7 billion is accounted for by children with 'low-functioning' autism living with their families, £72 million by children with 'low-functioning' autism living in residential or foster placements, and £1 million by children with 'high-

functioning' autism living with their families. It is estimated that only a small cost (£3 million) is accounted for by pre-school children, which begs the question, if there was increased investment in children with autism in the early years, for example, for early intervention programmes, would there be a reduction in the high costs of autism in adulthood? Knapp et al. (2007 & 2009) states that a greater availability of 'effective early interventions' may reduce the impact of autism on the UK economy, as well as improve the quality of life for people with autism and their families.

The recognition that little funding is spent on children with autism in the early years is an enormous step towards increased public spending on intervention programmes to support these children and their families. Unfortunately, there is little empirical research to support the efficacy of these interventions, highlighting the immediate need for empirically sound early intervention studies.

2.3 THE IMPACT OF EARLY INTERVENTION

2.3.1 Developmental Trajectories

There are few documented longitudinal studies which help us to understand the developmental trajectories of this population of children. However, there are some studies which have examined the stability of IQ and language (Venter, Lord & Schopler, 1992; Sigman & McGovern, 2005) as early predictors of later outcome (Charman, 2003; Sigman & Ruskin, 1999). Using standardised interviews with parents (Piven, Harper, Palmer, & Arndt, 1996; Charman, Taylor, Drew, Cockerill, Brown, & Baird, 2005) studies have shown that social and communicative difficulties can improve significantly with time and that autistic symptomatology is liable to change. Charman et al. (2005) reported less movement, however, in the area of restricted and repetitive behaviours, with parents reporting little change over time. Findings of this sort have led to the

suggestion that there might be different developmental trajectories for each of the symptom domains (Charman et al., 2005). This issue is important as further studies in this area may help in establishing early precursors for later development and assist in targeting behaviours in studies of early intervention.

Prevalence figures raise the question of whether there are interventions that are more or less suitable for particular sub-groups of individuals with autism. The nature of autism and the fact that individuals with autism do not form a homogeneous group, demands highly individualised approaches to intervention. As Howlin (2010) states, there is, as yet, no evidence that any one programme is superior to all others and that large individual differences in response to intervention suggest that the focus of research,

“now needs to shift to the study of which components of therapy work best for which children and under which condition.” (pg. 133).

Additionally, autism and autistic spectrum disorders are disorders that affect many aspects of thinking and learning. Cognitive deficits, including learning difficulties, are often interwoven with social and communication difficulties, which can make it impossible to disentangle one difficulty from another. Educational interventions cannot therefore assume a typical sequence of learning for these children and they should be individualised in order to address individual profiles of development (NRC, Lord & McGee, 2001). For example, a more verbal population may be able to participate better in group settings, whereas a non-verbal group may require considerable visual and individual support. There may also be sensory issues which cut across all kinds of interventions (Marwick, et al., 2005). Newson (1979) stated that it is important to address ‘the whole nature of autism’ and interventions that focus on a single aspect of the condition,

“miss the point that every kind of impairment in autism has links with every other impairment in the syndrome” (Cumine & Leach, 2002 pg. 39).

She therefore believed that a combination of elements from different approaches might be the most effective intervention. Anderson and Romanczyk (1999), Freeman (1997) and Schreibman and Winter (2003) also assert that there is no one single treatment that is effective for every child with autism, and they acknowledge that intervention plans should be tailored to meet the specific needs of the child with autism and his/her family. They state that a combination of treatment plans may be necessary or may supplement the educational or behavioural treatment plan in order to maximise outcomes.

2.3.2 Intervention Programmes

As autism interventions vary widely in their approach and methodology, early intervention programmes and schools preparing to serve children with autism face great difficulty in determining which interventions are most appropriate. Early intervention is widely perceived as the key to successful control of the manifestation of autistic behaviours, the reduction of some of the symptoms and the enhancement of outcomes (Lovaas, 1987; Sines, 1996; Howlin, 1997; Mesibov, 1997; Sheinkopf & Siegel, 1998) in terms of language, communication, social behaviour, developmental rates and cognitive ability and educational attainment (Howlin & Rutter, 1987, Rogers, 1996). Early intervention, therefore, is seen as an essential component to mainstream educational placement (where appropriate) for children with autism (Dawson & Osterling, 1997; Howlin & Moore, 1997; Rogers, 1996; Durrand & Carr, 1991), yet only a few early intervention treatments, particularly those using applied behavioural analysis, are supported by data where changes in the child can be documented as a result of taking part.

Early intervention is intended to target differences between the skills of children who are at risk, or already have developmental delays, and the skills of their typically

developing peers. These discrepancies may be initially small, but they are generally believed to increase through the passage of time (Guralnick, 1998; Ramey & Ramey, 1998). However, developmental trajectories are not final, even for children with known risk factors or disabilities. Each child's progress can be influenced by a number of factors, and the widespread hope for early intervention is that children can be placed on a 'normative developmental trajectory' and thus continue to show optimal development after the intervention programme ends. Ramey and Ramey (1998) posit a 'zone of modifiability,' a period of time during which the precise developmental trajectory for children at risk is likely to be determined by timing, intensity and appropriateness of treatment. The likelihood that effective early intervention can produce lasting neurobiological and behavioural changes has also been suggested by research (Dawson & Fischer, 1994; Shore, 1997; Hannigan & Berman, 2000), showing that early experiences play a critical role in shaping brain architecture as well as brain functioning.

In recent years, alongside the burgeoning range of theories to explain autism, there has been a dramatic increase in the number and range of intervention approaches. Some of these have been designed specifically for autism, whilst others are adaptations of approaches found to help children and adults with a variety of other difficulties. Each approach stems from a particular understanding of autism, its nature and causes, and aims to develop a way of compensating for the perceived deficits, or enhancing the perceived strengths. Parents of children with autism, who are often desperate for results, are particularly vulnerable to the introduction of new treatments. Goin-Kochel, Myers and MacKintosh (2007) note that the typical parent of a child with autism has tried at least 7 to 9 different therapies, many of which do not have an evidence base.

Approaches to intervention differ in their theoretical basis and consequent intervention paradigms. Intervention programmes include those that provide a structured education

setting, behavioural approaches which shape and modify behaviours, developmental interactive approaches, which aim to develop social and communicative processes through naturalistic interaction, and cognitive approaches, which aim to teach the child through co-construction of shared meanings (Marwick, Dunlop, & MacKay, 2005). Various claims have been made about the specific effects of intervention programmes, with a general consensus that early intervention is valuable and the more intensive the intervention, the greater the gains, despite variability in outcomes within the groups of children treated (Symes, Remington & Brown, 2006).

Systemic reviews of interventions (Jordan, Jones, & Murray, 1998; Howlin, 1998; Francis, 2005) are clear that no one effective approach to intervention exists, and due to the diversity of the autism population, this would appear entirely appropriate. All of the intervention options lay claim to some success for some children (Howlin, 1998; Jordan et al., 1998), yet interventions based upon a behavioural model currently benefit from the strongest research validation for effectiveness in autism (Schreibman & Winter, 2003), and remain largely unchallenged. There are, however, limitations regarding the conclusions that can be drawn concerning the effectiveness of early intervention in autism. No firm conclusions can be drawn yet regarding which types of interventions work best for different children (e.g., verbal versus nonverbal) or how much intervention is needed in order to be maximally effective. This is due to researchers using different methods for characterising individual differences in children and for quantifying progress. In order for meta-analyses to take place there is a need for agreement between researchers on how children are characterised and what constitutes progress over time.

The researcher believes that the primary goals of education for children with autism should be to foster development in a positive direction, promote learning, reduce problem behaviours and reduce family stress. Essential components of effective programmes for children with autism lay emphasis on functional activities and skills

needed to be successful in the real world, chronologically age appropriate activities, the ability to take part in both school and non school activities and social integration to the maximum possible degree. For children with autism, education must foster acquisition of not only academic skills but also socialisation, adaptive skills, language and communication, and reduction of challenging behaviour.

The following section gives an overview of intervention programmes that have been shown to be effective for pre-school children with autism. The researcher does question what exactly is meant by 'effective,' as each programme lays claim to having a 'positive impact' in different ways.

2.3.2.1 Early Intensive Behavioural Intervention (EIBI)

Behavioural approaches have been used in the UK with children with autism for many years and many approaches to autism intervention use behavioural approaches as part of their programme (Jordan, et al., 1998). Applied Behavioural Analysis is based on the theory that all behaviour is learned and that it is governed by its antecedents and consequences. This is based on Skinner's theory of 'operant conditioning' which was proposed in the 1960s. The foundation of the approach is that learning can be reduced to the repetition of responses, which increase with reward. ABA breaks down skills into a series of small steps which are then used as a teaching programme for a child. In 'discrete trial learning' each step is used as a learning goal, in a single trial, successful completion meets with a reward.

Over the past 40 years a large body of literature has shown the successful use of Applied Behavioural Analysis based procedures to reduce problem behaviour and increase appropriate skills for individuals with learning disabilities, autism, and related disorders. Research in this area continues to increase dramatically, a trend that

appears to be motivated by the reported success of behavioural interventions. This has increased the amount of funding in this area, especially as there is a clear argument that early intervention could save millions of dollars/pounds in long term care for this population. There are more reviews that focus on EIBI than any other intervention for children with autism, which underscores the perceived critical nature of this problem and treatment paradigm in the rapidly increasing range of autism interventions.

Out of the six EIBI papers (Hwang & Hughes, 2000; McConnell, 2002; Rogers, 2000; Stahmer, 1999; Terpstra, Higgins & Pierce, 2002) reviewed by Matson & Smith (2008) it was concluded that interpretations of the data vary considerably, from the conclusion that EIBI are '*widely acknowledged*' as the best empirically validated interventions to the conclusion that the *long term effects of EIBI are 'questionable'* (Matson & Smith, 2008, pg. 63). However, there appears to be a number of emerging themes. These include the call for more rigorous methodology and the need to look at certain child factors when making conclusions based on outcome data. Child factors that should be included in the research in order to draw firmer conclusions from the findings include: the age at which the child starts treatment, their cognitive abilities, the context, hours of treatment per week, and who provides the treatment.

To date, research into the effects of EIBI is more extensive than any other early intervention programme for this population. It therefore stands alone as one of the documented evidence based treatment for young children with autism which has been shown to be most effective. Although this is the case, there are a number of methodological flaws in the research which need to be taken into account when interpreting the results of such studies. These include: lack of or inadequate control groups, variations in measures of the same construct pre and post test, different measures of cognition and lack of measures of autism core symptoms or challenging behaviours. The latter two, in the researcher's view, are essential, as logically the point of any intervention programme for this group of children would be to improve difficulties

in core symptomology (communication and social interaction) and challenging behaviour (if present). Additionally, very little attention is paid to parent satisfaction and the social validity of the intervention. Including the parent's views of their child's progress is essential as the literature clearly shows that the quality of parent-child interactions has a significant effect on the child's progress. These interactions appear to be affected by the parent's personal views of their child (including acceptance) during the intervention.

2.3.2.2 Inclusion and naturalistic interventions

Inclusive education is a process involving the restructuring of the curriculum and classroom organisation. This distinguishes it from integration, which focuses on the placement of an individual or group, and that individual or group having to adapt to what the school is able to offer. Inclusion for young children with disabilities has been based on a three-part rationale as described by Bricker (1978 & 1995). Firstly, the regular education curriculum and access to a typically developing peer group will provide learning opportunities that do not exist in special education classes, where only children with disabilities are present (Bricker, 1995). Secondly, law (Special Educational Needs Code of Practice, 2001) recommends that, where possible, children with disabilities receive a free, appropriate education in settings that are typical and that include same-aged peers. In other words, children should be educated in the "least restrictive environment" possible. Thirdly, many individuals see the inclusion of a child in a classroom, as well as in his or her community, as the most appropriate and ethical placement, given that it meets the child's and family's needs.

Researchers have documented that students with disabilities, including students with autism, who are fully included in mainstream settings, display higher levels of engagement and social interaction, give and receive higher levels of social support, have larger friendship networks, and have developmentally more advanced

individualised education plan goals than their counterparts in special education placements (Fryxell & Kennedy, 1995; Hunt, Farron-Davis, Beckstead, Curtis, & Goetz, 1994; Harrower & Dunlap, 2001). Additionally, there is evidence that these children make greater gains on standardised measures of language and social competence (Jenkins, Odom, & Speltz, 1989) than their peers in special education classes (Evans, Salisbury, Palombaro, Berryman, & Hollowood, 1992; Hunt, Farron-Davis, Beckstead, Curtis, & Goetz, 1994; Harrower & Dunlap, 2001). Due to children with autism spending significantly less time in interactions with their peers than typically developing children, it is fair to say that including them in settings where social interaction is encouraged between all children, could significantly impact on this area of their development.

Evidence also suggests that enrolment in inclusive programmes does not have any negative effects for typically developing children (Odom, DeKlyen, & Jenkins, 1984), but supports social integration, which promotes interactions among children with and without disabilities. Additionally, families of children with and without disabilities enrolled in inclusive settings generally have positive attitudes toward inclusion (Guralnick, 1994; Peck, Carlson, & Helmstetter, 1992). The increased social contact between children with and without disabilities (Miller, Strain, Boyd, Hunsicker, & Wu, 1992; Peck, Carlson, & Helmstetter, 1992) and children's increased sensitivity and acceptance of differences (Green & Stoneman, 1989; Reichart, Lynch, Anderson, Svobodney, DiCola, & Mercur, 1989), are reported as potential benefits.

Within the pre-school classroom inclusion of pupils with autism and other disabilities should be a simpler process than that of the primary or secondary education classroom. This is due to teaching practices for preschool-aged children differing from those for older children. Accepted instructional strategies for both young children with disabilities and typically developing children encourage child-initiated learning and children's active physical engagement with each other and with the environment (Wolery & Bredekamp, 1995; Wolery & Sainato, 1996; DCFS, 2009). In contrast,

instruction at the primary and secondary school levels is more likely to be teacher-directed. If early intervention is the key to successful inclusion of pupils with autism in the mainstream classroom, it is indeed logical that they should, therefore, be included in mainstream education from the earliest stage possible.

2.3.2.3 Parent-Implemented Interventions

The involvement of parents in implementing intervention strategies designed to help their children with autism stretches back to the 1970's (Schopler & Reichler, 1971) and continues to be highlighted in the literature. This is due to evidence suggesting that earlier intervention for children with autism is essential (Rogers, 1996), which logically implies the involvement of parents. As mentioned earlier in this chapter, researchers have reported strong relationships between parent-child interactions and children's cognitive and socio-emotional development (Baker & Feinfield, 2003). Training parents as co-therapists allows consistent handling of the child in different settings. Proactive and positive interventions strengthen parents' skills in natural settings, promoting increased confidence and reducing parental stress (Gavidia-Payne & Hudson, 2002). In their reviews of the literature, Koegel (2000) and Rogers (2000) emphasised the importance of parent-implemented interventions and the magnitude of social and communicative gains that parents could accomplish with their children.

Siller and Sigman (2002) were amongst the first researchers to examine the relationship between parenting style and the development of children with autism. They found that children with autism, whose parents showed greater synchrony during play interaction, were more likely to have better developed communication skills. More recently, Carter, Grossman, & Wachtel (2007) demonstrated that global ratings of maternal supportive engagement (the mother offering a supportive, encouraging environment) and cognitive engagement (stimulation of verbal and non-verbal

development) were associated with language gains in a young sample of children with autism over the course of a year.

Recent studies that focussed on early intervention have gone beyond cognitive development and behaviour problem reduction as outcome indicators, to look more broadly at family and child functioning. Feldman & Werner (2002) found that behavioural-parent training resulted in decreased family stress, increased parental self-efficacy and improved child and family quality of life. Parents spend so much more time with their children, and it is therefore recognized that they can often achieve a greater understanding of their child's needs and provide unique insight into creating an intervention plan. Teaching children in their natural environments is an important component of early intervention (Dunlap, Ester, Langhans, & Fox, 2006; Sandall, Hemmeter, Smith & McLean, 2005) and natural environments and daily routines are preferred intervention settings for children with a range of abilities (Kashinath, Woods, & Goldstein, 2006). Koegel (2000) noted that parent education programmes requiring parents to set aside specific time in their schedules to work one-to-one with their children increases parental stress levels, whereas, naturalistic programmes, which promote an understanding of the child, do not.

Meadan, Ostrosky, Zaghlawan and Yu (2009) reviewed a total of twelve studies published between 1997 and 2007 outlining the results of parent-implemented interventions for children with autism. All of the studies revealed positive results both for parents and children, and reported that parents were able to learn and implement new strategies with their children in natural environments. Parents' positive behaviour changes also resulted in positive changes in children's target behaviours. Meaden et al. (2009) concluded that when parents assume the role of interventionists there is an increased likelihood that they will follow up with their children on the newly learned skills and encourage them to continue to improve their skills. Additionally, as more parents become more knowledgeable about evidence-based interventions they can

serve as mentors to other families and spread information on recommended practices to other families with children with autism. Providing parents with the knowledge and skills to work with their child in naturalistic settings can give parents a sense of control, increase their feelings of relatedness with their child and their sense of competence as parents, thereby decreasing emotional stress and facilitating well-being. A better understanding of the relationship between resolution and parent-child interactions and other social-emotional outcomes may, therefore, have important implications for early intervention.

2.4 THE CURRENT CONTEXT

2.4.1 The EarlyBird Programme

In 1997 the National Autistic Society in the UK developed an early intervention programme that focuses on supporting parents and on building parental confidence. The programme uses an eclectic collection of established practice within a short-term post diagnosis, parent focused programme. The content of the NAS EarlyBird Programme draws from practice in the field of autism and combines aspects of the 'Hanen' programme (Sussman, 1999) for early language development (e.g. structure of the sessions, home visits etc.) with behavioural principles illustrated in 'TEACCH' (Schopler, 1971) (Treatment and Education of Autistic and related Communication-handicapped Children). In addition, time is spent identifying the function of various behaviours and the effect of natural reinforcers. Aspects from PECS (Picture Exchange Communication System) (Bondy & Frost, 1996) are also incorporated.

The programme is based on the assumptions that early intervention is recommended as soon as possible after diagnosis for children on the autistic spectrum (Peacock, Forrest & Mills, 1996; Rogers, 1996; Dawson & Osterling, 1997), and that the involvement of parents (or the primary carers) in early intervention has a positive influence on outcomes (Guralnick, 1998; Kasari & Sigman, 1997). Partnership with parents is emphasised and EarlyBird works with a small group of families at a time over a period of three months, combining weekly group training sessions for parents with individualised home visits. Three places are allocated to each family, two for parent/carers and one for a practitioner. At least one parent commits to attending every training session, and if a practitioner is involved they are asked to give the same level of commitment. The aim of the programme is to help parents to learn about autism, to build social communication and to analyse and use structure so as to prevent inappropriate behaviours, thereby making the parents feel more confident and in control. Where a practitioner attends, the aim is to encourage a consistent approach between home and pre-school. The use of video and the group dynamic amongst the families are viewed as important components of the programme. The home visits help individualise what the parents have learned during group training sessions and video feedback is given to help parents evaluate their own progress.

2.4.2 Aims of the EarlyBird Programme

The primary aim of the programme is to provide training to parents of pre-school children with autism in effective and consistent practical strategies (based on theoretical models) which can help them to understand and manage the effects of autism on their child's development (behaviour and communication).

“The underlying philosophy of EarlyBird is to provide hope: EarlyBird does not claim to cure autism” (Hardy, 1999, pg. 54)

The secondary aim of the programme is to develop a model of 'good practice' in early intervention for families of pre-school children with autism, which can be used elsewhere. The EarlyBird Programme aims to give parents confidence in how to handle their child, insight into their child's problems, and knowledge of how to pause and understand their child's behaviour and plan strategies for improvement.

2.4.3 Structure and content of the EarlyBird Programme

EarlyBird incorporates individual work with parents at home and group sessions. Within the group sessions small groups are created so that parents work together during the programme. A total of eight group sessions and three home visits are completed with each family. Each group session is held at the same time each week and is three hours long. Different methods of teaching are incorporated, including practical exercises, the use of autism-specific video clips, and the demonstration of simple practical techniques.

The programme content is aimed at targeting the needs of parents living with a pre-school child, but covers children across the autism spectrum and developmental stages. The programme uses autism specific materials, specifically the Parent Book (Shields, 1999) which provides factual information together with guidelines for homework tasks and preparation for home visits. The EarlyBird Video (Shields, 1999) supports all sessions and uses interviews with parents in the UK who have preschool children with autism as examples to help current parents learn from those who have participated in the programme previously.

2.4.4 Licensed Users

Since January 2000 the EarlyBird Centre has regularly trained teams of professionals from across the UK and abroad to run the programme in their local areas. In June 2008, there were 250 licensed teams comprising 1,300 individual licensed users who have run the programme with more than 6,000 families. An evaluation study has accompanied the development of the programme to ensure that it remains effective when disseminated via licensed users (Shields & Simpson 2004).

2.4.5 Efficacy Studies

The two year pilot EarlyBird Project was accompanied by an independently evaluated efficacy study (Hardy, 1999). The aims of the studies were to explore whether there were gains or improvements during the control period and the intervention period, or whether there was an improvement from just prior to the intervention period to the end of the follow-up period (six months later); and finally, whether there were any differences between the EarlyBird Centre (based in South Yorkshire, UK) and Licensed User sites. The findings of the pilot study have now been replicated in a study of 119 families participating in the programme at licensed user sites around the UK and beyond (Shields & Simpson, 2004). The studies found evidence of significantly reduced stress and modified communication style in participating parents who also showed more positive perceptions of their children. It was reported (Hardy, 1999) that these effects were still present at follow-up, six months after the programme.

The use of a delayed treatment control paradigm was used, where parents waiting to take part in the EarlyBird Programme at a later stage formed the control group, in both the Hardy (1999) and Shields and Simpson (2004) studies. Hardy (1999) examined 30 pilot families and found evidence supporting the expectation that participating parents would become less stressed, adjust their communication style in accordance with the

recommendations of the programme and perceive their children more positively. The Shields and Simpson (2004) study built on the pilot study and examined a larger body of data from families attending the EarlyBird Centre and from families attending licensed user run programmes. The overall results for both studies were consistent for all families and it was concluded that parents become less stressed, adapt the style of communication used with their child, and perceive their child more positively following participation in the NAS EarlyBird Programme (Hardy, 1999; Shields & Simpson, 2004).

2.5 RESEARCH QUESTIONS

There are few documented longitudinal studies which help us to understand the developmental trajectories of this population of children. Exploring the patterns of development of pre-school children with autism over a short period of time using standardised measures, observations and parental interview data could help professionals and researchers in a number of ways. These include:

- A greater ability to disentangle maturation gains from treatment gains, where children are involved in early intervention programmes.
- A greater understanding of the development that could occur in the early years before formal school placement. This may help professionals and Local Authorities provide more appropriate individualised targeted support to children with autism based on their individual developmental profiles.

Therefore, the current study aims to answer the following research question:

- 1. Can we measure the individual patterns of development, and the factors that appear to be important in encouraging any measured development, of a group of pre-school children with autism in aspects of their cognitive functioning, communication and language skills, social interaction and adaptive behaviour?***

A number of researchers (Dillenburger, Keenan, Gallagher & McElhinney, 2004; Kohler, 1999) have highlighted the importance of including parents' views in studies where their children are being studied. This increases the social validity of the study, as if parents verbally report that they have seen changes occurring in their children, whether such changes have occurred or not, then the value of the research is increased. Where research is seen as being socially valid, the likelihood of parents being willing to take part in future studies also increases. The researcher aims to address this criticism of other studies, where parents' views have not been gathered, by including the parents' views in this study. In addition, data gathered from parental interviews may also contribute towards exploring individual patterns of development, as well as any factors that may have contributed to developmental changes explored in Research Question 1.

An exploration of the parents' views with regards to the support that they had received in the Local Authority where the research took part is deemed important as the Local Authority only provide the EarlyBird Programme as a means of support and intervention for children in the early years. However, it appears that a large proportion of parents who have children with autism are not accessing this service. Research has documented that the period immediately following a diagnosis of autism can be distressing (Pianta & Marvin, 1993).. Additionally, some research has shown that the child with autism can have a negative impact on the family. However, research does not detail how this impact could be reduced. Appropriate support for these parents could, therefore, be highly beneficial.

Therefore, the current study also aims to answer the following research question:

- 2. *What are the views of parents participating and not participating in the Early Bird Programme on:***
 - ***Perceived gains in their children's development?***

- *The Impact of the EarlyBird Programme and/or other specialist or non-specialist provision?*
- *The Impact on the family of a diagnosis of autism?*
- *The factors that appear to be important in reducing the negative impact of a diagnosis of autism on the family?*
- *Challenges to access of the EarlyBird Programme?*

2.7 SUMMARY

This chapter has presented some of the current literature on autism, with a main focus on the impacts of autism on the family, education and society, highlighting the need for early intervention services for this population of children. The following chapter will present an outline of the methodology detailing the design, participant profiles, measures used and the procedure that was followed in order to answer the research questions presented above.

CHAPTER 3

METHODOLOGY

This chapter aims to outline the methodology of the current research. The researcher presents the rationale for the research design, outlines participant profiles, the recruitment procedure, and the methods used. There is also a review of the pertinent ethical issues and research design constraints posed by the current research.

3.1 DESIGN

The current study adopts a multiple case study design within a mixed methodology framework. The multiple case study approach was chosen for this study because characteristics of children with autism differ widely from each other and large groups of children with autism who have similar characteristics are difficult to recruit. Moreover, large group designs obscure findings at the level of the individual unit, and fail to provide useful information about the individual children. The case study method affords a desirable alternative to an experimental design for examining hypothesized theoretical links between related events over time (Yin, 2003).

The use of a multiple case study design, allows the researcher to explore the individual within his real life context using multiple sources of evidence, as described by Robson (2002) and Yin (1981, 1994). Converging methods of inquiry is considered integral to case study approaches. The philosophical distinctions between qualitative and quantitative research are not regarded as incompatible in this method; instead they are valued for their ability to explore more broadly the phenomenon under investigation. The findings of a case study are described as more likely to be convincing and accurate if they are based on several different sources of corroborative information

(Yin, 1994). Therefore, multiple sources of evidence were used to illuminate different aspects of the research aim and objectives.

The mixed methods approach was selected as it has the potential to reduce some of the problems associated with singular methods. By utilizing quantitative and qualitative techniques within the same framework, mixed methods research can incorporate the strengths of both methodologies (Sechrest & Sidana, 1995). Most importantly, the researcher believes that a mixed methods approach is more likely to address the distinctly different research questions in this study. This design encourages both depth and breadth when gaining a deeper understanding of individual patterns of development of all the children in the study, as well as the impact of having a child with autism on the family and the parental perceptions of their child's development. As Burke-Johnson and Onwuegbuzie (2004) note, it is better to select methods and approaches with respect to their underlying research questions, rather than with regard to some '*preconceived biases about which research paradigm should have hegemony in Social Sciences research*' (pg. 23).

The use of mixed methods research in education and social and behavioural research is being described as the third methodological paradigm, alongside the traditional qualitative and quantitative paradigms (Johnson & Onwuegbuzie 2004; Tashakkori & Teddlie, 2003) with an underlying philosophical paradigm of pragmatism. This paradigm argues that there are multiple realities that research can explore, with the primary focus placed on the research questions and what methods will best answer the question (Mertens, 2005; Creswell & Plano Clark, 2007). The researcher subscribes to this philosophical view point due to current training as a Trainee Educational Psychologist. This impacts on the researcher's world view, as problems are typically assessed and explored through the use of multiple sources of data in order to produce a view of the problem at a particular point in time and integrate multiple perspectives (Powell, Mihala, Onwuegbuzie, Suldo & Daley, 2008). This background, and therefore

this study, aligns with the world view of pragmatism where the design that best answers the research questions has been chosen, opening up the possibilities for scientific enquiry through both quantitative and qualitative methods.

It is clear that the individual differences of the children, as well as the small sample size, will inhibit the generalisation of data to a larger population. However, as Jordan (1999) and Howlin (1998, 2010) argue, individual differences between people with autism makes it almost impossible to meaningfully compare data between 'groups.' Therefore, firm conclusions cannot be drawn about effectiveness due to the heterogeneity of the samples within intervention research. Jordan (1999) stated that it is hardly ever possible to conduct true experiments in real-life settings due to it being neither ethical nor feasible to have random assignment of individuals with autism to experimental and control groups or to find large numbers of individuals with autism who have similar characteristics.

The individual patterns of development of the children over the time period of the study were explored. Additionally, their parent's views were gathered in order to explore their experiences of the impact of a diagnosis of autism on the family, their perceptions of their child's development over the course of the study, and factors that they feel had contributed to any reported developmental gains. All six children's parents had been offered the opportunity to take part in the EarlyBird Programme. However, only three decided to sign up to take part in the 13-week programme, and three did not. The study, therefore also explored the perceptions of those parents who took part in the EarlyBird Programme about its effectiveness. The three parents who took part in the EarlyBird Programme formed the EarlyBird group of parents and the three parents who did not take part in the programme formed the non-EarlyBird group of parents.

In the current exploratory study, six case studies are incorporated into the design. Data were collected for the children at two time points. Initial data collection (time 1) took place before the EarlyBird group of parents started the EarlyBird Programme and secondary data collection (time 2) took place approximately six months later. The research methods in this study incorporated semi-structured interviews with five of the six parents (one parent did not give consent to be interviewed) which were conducted at the second time point, informal unstructured observations of all the children at both time points, standardised assessment questionnaires (Vineland-II, Gilliam Autism Rating Scales-2, Strengths and Difficulties Questionnaire) completed by the parents at both time points and psychometric assessments (British Ability Scales-II) of the children's cognitive abilities which were conducted at both time points.

3.2 ETHICAL APPROVAL

The planning and implementation of this study adheres to the British Psychological Society Code of Ethics and Conduct (2006). Ethical consent was gained from the Departmental Ethics Committee at the Institute of Education, University of London, as well as the local authority in which the research took place (Appendix 1). An information sheet (Appendix 2) outlining the details of the study, its design and purpose was included with the consent forms. This sheet provided the parents with information as to why the study was taking place, why they had been selected to take part, how their children would be assessed, and what would be done with the results. Parents were also informed of their right to withdraw at any time. The researcher ensured that written, signed parental consent was gained for all children (Appendix 3). Their consent to take part in semi-structured interviews, and for the trainers of the EarlyBird Programme to share information on their attendance as well as their completed questionnaires, was also gained.

Consent was gained from the parents and teachers of the pre-schools for observations to take place outside the home environment. All participants were assigned pseudonyms for identification so that their identities were kept confidential. The researcher ensured that all data collected was stored in a locked fire proof safe. Only the researcher had access to this cabinet.

The parents were informed of the results of the cognitive assessments (initial assessment and secondary assessment) of their child and information was shared in a professional and sensitive manner. A simple template, which was created by a psychology assistant within the local authority's Educational Psychology Service, was used to report the scores and offer interpretation of the scales used after administering the Early Years BAS-II. This was done for all the children in the study. The EarlyBird Programme directors and the parents will have the findings of the research shared with them at a later date. If the research was to be published all participants would be informed. The researcher has a current and up to date criminal records check (CRB) due to the nature of employment as a Trainee Educational Psychologist.

3.3 PARTICIPANTS

3.3.1 Selection

The participants were selected following referral to the EarlyBird Programme by a paediatrician after identification of the child as having autism. Parents who requested information on the programme were asked if they wished to take part in the study. All parents, regardless of whether they were going to take part in the programme or not, were given information about the study by the EarlyBird Programme director. Parents who were interested in the study consented to their contact information being passed to the researcher in order for telephone contact to be made. Three parents that signed up

to complete the three month EarlyBird Programme formed the EarlyBird group of parents, and three parents that decided not to take part in the EarlyBird Programme formed the non-EarlyBird group of parents.

The EarlyBird Programme works with groups of six families at a time. Three families taking part in the programme agreed to take part in the research. Each family had two carers on the programme (the parents), with one carer consistently allocated as the 'main carer.' The 'main carer' was involved in completing the measures involved in this research study and the semi-structured interview that took place six months after completion of the programme. The 'main carer' was also required to attend all group sessions and home visits.

Three families not taking part in the EarlyBird Programme agreed to take part in the research. A 'main carer' was allocated, as with the EarlyBird Programme, in order to ensure that one parent was responsible for completing the measures involved in the research study and the semi-structured interview that took place six months after the EarlyBird group of parents had completed the EarlyBird Programme.

3.3.2 Inclusion Criteria

All children included in the study needed to be of pre-school age at the start of the study (under 5 years) and have been diagnosed by a multi-professional diagnostic team as having autism.

3.3.3 Participant profiles

Six children took part in the study; Jack, Christopher, Rory, Oscar, William and Matthew (pseudonyms have been used to identify the children). All parents were

required to complete an information sheet about their child and family at the time of initial data collection (Appendix 5). The categories used for ethnicity and language and socio-economic status are based on the National Population Census categories¹. The following participant profiles present the information that was gathered about each child and their family.

3.3.3.1. Jack

Jack is male and at the start of the study was 4 years 5 months (53 months). He has a diagnosis of autism and Fragile X Syndrome. Jack had been diagnosed as having autism by a Multi-Disciplinary Team within the Local Authority where the research was taking place. Jack attended a mainstream pre-school at the start of the study, and at the time of secondary data collection had transferred to a mainstream primary school. At the time of gathering information about Jack his mother reported that he was seeing an Occupational Therapist and a Physiotherapist and was going to be taking part in Speech and Language Therapy in the near future (at the time of secondary data collection Jack had not taken part in any Speech Therapy sessions). Jack did not take any medication throughout the duration of the study. Jack's family described themselves as a 'White-Other' family living in a suburban area. They reported that their Socio-Economic Status was 'High.' Jack's parents were educated up to postgraduate level. Jack and his family speak English at home and there is no exposure to other languages within the family home. Jack is one of three children; he has two older female siblings. Jack is verbal. Jack's parents took part in the 13-week EarlyBird Programme.

3.3.3.2 Christopher

¹ Socio Economic Status: High – above £40 000, Medium - £30 000 - £40 000

Christopher is male and at the start of the study was 3 years 11 months (47 months). He has a diagnosis of autism and had been diagnosed by a Multi-Disciplinary Team within the Local Authority where the research took place. Christopher attended a mainstream pre-school at the start of the study, and at the time of secondary data collection had transferred to a mainstream primary school. Christopher did not take any medication throughout the duration of the study and received no additional professional interventions whilst the study was taking place. Christopher's family described themselves as a 'White-British' family living in a rural area. They reported that their Socio-Economic Status was 'High.' Christopher's parents were educated up to postgraduate level. Christopher and his family speak English at home and there is no exposure to other languages within the family home. Christopher is one of two children; he has one younger female sibling. Christopher is verbal. Christopher's parents took part in the 13-week EarlyBird Programme.

3.3.3.3 Rory

Rory is male and at the start of the study was 2 years 10 months (34 months). He has a diagnosis of autism and had been diagnosed by a Multi-Disciplinary Team within the Local Authority where the research took place. Rory attended a mainstream pre-school at the start of the study, and at the time of secondary data collection had transferred to a different mainstream pre-school. Rory did not take any medication throughout the duration of the study and received no additional professional interventions whilst the study was taking place. Rory's family described themselves as a 'Mixed Race' family living in an urban area. They reported that their Socio-Economic Status was 'High.' Rory's parents were educated up to postgraduate level. Rory and his family speak English at home and there is no exposure to other languages within the family home. Rory is one of two children; he has one younger male sibling. Rory is verbal. Rory's parents took part in the 13-week EarlyBird Programme.

3.3.3.4 Oscar

Oscar is male and at the start of the study was 4 years 3 months (52 months). He has a diagnosis of autism and had been diagnosed by a Multi-Disciplinary Team within the Local Authority where the research took place. Oscar attended a mainstream pre-school at the start of the study, and at the time of secondary data collection had transferred to a mainstream primary school. Oscar did not take any medication throughout the duration of the study and received no additional professional interventions whilst the study was taking place. Oscar's family described themselves as a 'White British' family living in a rural area. They reported that their Socio-Economic Status was 'High.' Oscar's parents were educated up to postgraduate level. Oscar and his family speak English at home and there is no exposure to other languages within the family home. Oscar is an only child. He is verbal, although his mother described his language as '*echolalic*' rather than '*functional*.' Oscar's parents did not take part in the 13-week EarlyBird Programme and Oscar's mother did not give consent for Oscar to be observed or for her to be interviewed by the researcher at the time of secondary data collection.

3.3.3.5 William

William is male and at the start of the study was 3 years 6 months (42 months). He has a diagnosis of autism and had been diagnosed by a Multi-Disciplinary Team within the Local Authority where the research took place. William attended a mainstream pre-school at the start of the study, and at the time of secondary data collection had transferred to a special needs primary school for children with autism and learning difficulties. William was taking melatonin throughout the duration of the study. He received no additional professional interventions, although due to being in a specialist

provision he was receiving more intense 1:1 teaching throughout the school day for the last three months of the study. William's family described themselves as a 'White-British' family living in an urban area. They reported that their Socio-Economic Status was 'High.' William's parents were educated up to A-Level. William's family speak English at home and there is no exposure to other languages within the family home. William is one of two children; he has one younger male sibling. William is non-verbal. William's parents did not take part in the 13-week EarlyBird Programme.

3.3.3.6 Matthew

Matthew is male and at the start of the study was 3 years 4 months (40 months). He has a diagnosis of autism and had been diagnosed by a Multi-Disciplinary Team within the Local Authority where the research took place. Matthew attended a mainstream pre-school at the start of the study, and at the time of secondary data collection had transferred to a different mainstream pre-school. Matthew did not take any medication throughout the duration of the study. He received 1:1 Speech and Language Therapy for 30 minutes every week whilst the study was taking place. Matthew's family described themselves as a 'White-British' family living in a suburban area. They reported that their Socio-Economic Status was 'Medium.' Matthew's parents were educated up to undergraduate level. Matthew and his family speak English at home and there is no exposure to other languages within the family home. Matthew is one of two children; he has one older male sibling. Matthew is verbal. Matthew's parents did not take part in the 13-week EarlyBird Programme.

The following table provides a summary of all the children who took part in the study:

Name	Age (yrs)	Siblings	Ethnicity	Socio-Economic Status	Locale	Other Support	Parents doing EB
Jack	4.5	2 older	WO	High	Suburban	Occupational Therapy Physiotherapy	Yes
Christopher	3.11	1 younger	WB	High	Rural	None	Yes
Rory	2.10	1 younger	MR	High	Urban	None	Yes
Oscar	4.3	0	WB	High	Rural	None	No
William	3.6	1 younger	WB	High	Urban	None	No
Matthew	3.4	1 older	WB	Medium	Suburban	Speech Therapy	No

Table 1: Participant Profiles
WO – White Other, WB – White British, MR – Mixed Race

3.4 THE SETTING

The EarlyBird Programme training sessions and workshops were held on Friday mornings (9.45 am – 12.45 pm) at a Community Centre within the main city centre. The programme was run by an Early Years Advisory Teacher and the Early Years Area Coordinator as part of the service offered by the Local Authority's Early Years and Childcare Service. Both trainers had been trained and licensed to deliver the programme. There were two additional staff that supported the programme by offering home visits where appropriate.

The children in the study continued to access their school environments over the time period of the study. All six children changed educational placement over the course of the study. They either moved from one pre-school to another pre-school or from preschool to primary school, depending on their age. William was the only child in the study who moved from a mainstream pre-school to a special primary school. Both Jack

and Matthew were receiving additional support, which also continued over the course of the study. Matthew received Speech and Language Therapy in his home environment and Jack received Occupational Therapy and Physiotherapy support in a clinic setting. No other children in the study received additional specialist support during the course of the study.

3.4.1 Cost of the EarlyBird Programme

Table 2 includes an approximate break down of the costs of running the EarlyBird Programme for approximately 20 families per year in the context of this study:

Resource	Cost in Pounds (£)
Trainers	16978
Hall hire	300
Refreshments for parents	100
Support to enable access to the programme (childcare, transport)	700
Support practitioner (home visits)	2000
Total cost per year	20078
Total cost per child per year	1003.98

Table 2: Cost of running the EarlyBird Programme

In summary, the total cost per child for parental involvement in the EarlyBird Programme is approximately £1003.98. This cost is not a burden to parents as the programme is funded by the Local Education Authority as part of the Early Years Inclusion Service.

3.5 SELECTION OF MEASURES

Multiple sources of data were collected in order to attempt to enhance the rigour of the research. This included: informal observations of the children, semi-structured interviews with five of the six parents (one parent did not give consent to be interviewed), standardised assessments of the children's cognitive abilities carried out by the researcher and standardised questionnaires, which were completed by the parents.

The initial data set for all the children was collected approximately one month prior to the EarlyBird group of parents starting the EarlyBird Programme (time 1). The second data set was collected approximately six months later, which was two months after the EarlyBird group of parents had completed the 13-week EarlyBird Programme (time 2). A six-month study time period was selected in order to reduce the impact of 'practice-effects' when re-assessing the children using the Early Years BAS-II. The BAS-II (Elliot, Smith & McCulloch, 1997, p. 200-202) test-retest studies are based on an interval of two to six weeks, and it is suggested that the examiner needs to be aware of practice effects when children are tested a few months after initial testing. It is recommended that re-testing does not take place within a six month period of the initial test and that any practice effect at three months or more is likely to be smaller.

The following measures were used in the study:

Measure	Outcome Measured	Type	Time	Children
Gilliam Autism Rating Scale – Second Edition (GARS -2)	Social Interaction Communication Stereotyped Behaviour Autism Severity	Rating scale and interview completed by parent	Time 1 and Time 2	All 6 children
Vineland Adaptive Behaviour Scales – Second Edition (Vineland-II)	Adaptive Behaviour -Communication -Social Interaction Skills -Adaptive Behaviour	Rating scale completed by parent	Time 1 and Time 2	All 6 children
Strengths and	Conduct Problems,	Rating scale	Time 1	All 6 children

Difficulties Questionnaire (SDQ)	Inattention/Hyperactivity, Emotional Symptoms, Peer Problems Prosocial behaviour	completed by parent	and Time 2	
British Ability Scales – Second Edition – Early Years Lower Level Core Scales (BAS II – Early Years)	Cognitive Ability	1:1 assessment of child	Time 1 and Time 2	4 of the 6 children initial data collection time point and 5 of the 6 children at secondary data collection time point
Semi Structured Interview	EB Programme Impacts of autism on the family Perceived Gains Challenges to access of the EB Programme	Researcher interviews parents	Time 2	EarlyBird and non-EarlyBird groups of parents
Unstructured Observation	Social interaction Play Communication Attention	Researcher observed child	Time 1 and Time 2	All 6 children at initial data collection time point, 5 of the 6 children at secondary data collection time point.

Table 3: Measures

3.5.1 Quantitative Data Collection

Four formal standardised measures were selected to explore individual patterns of development in aspects of cognitive functioning, communication and language skills, social interaction and adaptive behaviour of the children who took part in the study. The standardised questionnaires completed by the parents included; The ‘Gilliam Autism Rating Scale – Second Edition’ (GARS-2) (Gilliam, 2005), the ‘Vineland Adaptive Behaviour Scales – Second Edition’ (Vineland-II) (Sparrow, Cicchetti & Balla, 2005) and the ‘Strengths and Difficulties Questionnaire’ (SDQ) (Goodman, 1997). The ‘British Ability Scales – Second Edition – Early Years Lower Level Core Scales’ (BAS II – Early Years) (Elliott, Smith & McCulloch, 1997) were used to assess each child’s cognitive abilities in order to attempt to explore whether there are different patterns of development for the children according to their cognitive ability levels. The cognitive assessments were carried out by the researcher.

3.5.1.1 The Gilliam Autism Rating Scales – Second Edition (GARS-II)

The GARS-2 was selected in order to confirm that the participants have a diagnosis of autism, or meet the criteria for formal diagnosis. Matson (2007) highlighted the importance of researchers using an autism rating scale in order to account for issues of severity of autism. The GARS-2 was specifically selected over alternative autism rating scales due to the context in which the research was taking place where the scale is used across the county by Educational Psychologists and Paediatricians as an autism diagnostic tool. The GARS-2 was also used to explore changes in stereotyped behaviours, communication and social interaction of the children.

The GARS-2 was normed in the United States of America on a sample of 1,107 persons with autism between the ages of 2 and 22 years. Tests of reliability and validity demonstrated that the GARS-2 has strong psychometric characteristics and that Coefficients of reliability (internal consistency and test-retest) for the subscales and entire test are all large to very large in magnitude. The validity of GARS-2 was demonstrated by confirming that: (a) the items of the subscales are representative of the characteristics of autism; (b) the subscales are strongly related to each other and to performance of other tests that screen for autism; and (c) GARS-2 standard scores discriminate persons with autism from persons with other severe behavioral disorders and those with learning difficulties (Gilliam, 2005).

The GARS 2 consists of 42 clearly stated items that are divided into 3 subscales with 14 items each that describe specific, observable and measurable behaviours. A parent interview is provided so that examiners can interview parents about their child's first 3 years of life.

The first subscale, Stereotyped Behaviours, contains items 1-14. Items on this subscale describe stereotyped behaviours, motility disorders and other atypical

behaviours. The second subscale, Communication, contains items 15-28. These items describe verbal and nonverbal behaviours that are symptomatic of autism. The third subscale, Social Interaction, contains items 29-42. Items on this scale evaluate the individual's ability to relate appropriately to people, events and objects.

The GARS 2 scales must be rated by someone who knows the person well, for example a parent/carer or school teacher. The rater circles the appropriate value for each item (Table 4).

0	Never Observed	You have never seen the individual behave in this manner
1	Seldom Observed	Individual behaved in this manner 1-2 times per 6 hour period
2	Sometimes Observed	Individual behaves in this manner 3-4 times per 6 hour period
3	Frequently Observed	Individual behaves in this manner at least 5-6 times per 6 hour period.

Table 4: GARS ratings

A total raw score is computed for each of the subscales. The total is achieved by adding the raw scores for each item. Total raw scores can be converted to percentile ranks and to derived standard scores having a mean of 10 and a standard deviation of 3. The sum of the subscale standard scores can then be converted into the Autism Index (AI) and its percentile. Using the information recorded the examiner notes the probability that the individual has autism (Unlikely, Possibly, Very Likely) by comparing an individual's score with the normative sample. The AI has a mean of 100 and a standard deviation of 15 and is the most reliable of the scores generated on the GARS 2. The examiner is required to be a qualified Educational Psychologist, educational diagnostician, autism specialist, or Speech and Language Therapist.

The research on the GARS 2 is currently limited, although the GARS 2 has been described by Bradley-Johnson, Johnson and Vladescu (2008) as a 'technically sound' narrow-band measure which helps to verify eligibility for interventions as well as discriminate among conditions within the Autism Spectrum. Additionally, Legoff and Sherman (2006) used the Social Interaction subscale of the GARS 2 in their study and considered it to be an acceptable measure of autistic-type social behaviours. More recently the GARS-2 has been used in a UK study (Reed, Osborne & Corners, 2010) to assess the effectiveness of school placement for children with autism. This measure was found to be a 'good' measure of autism severity.

3.5.1.2 The Vineland Adaptive Behaviour Scales – Second Edition (Vineland-II)

The Vineland-II was selected as it contains domains particularly related to the developmental characteristics of autism (communication, social skills and play skills). In addition, given the lack of information on the stages and rate of development of pre-school children with autism the ability of this measure to provide overall age equivalent scores was considered important.

Adaptive behaviour is a critical part of assessing students who have or are suspected of having autism (Klin & Volkmar, 2000; Myles et al., 2007) and research supports the view that students with Autistic Spectrum Disorder/s demonstrate deficits in all areas of adaptive functioning (Myles et al., 2007). The use of a formal adaptive behaviour measure allows the assessor to determine the individual's level of functioning in daily tasks required to be successful in the home, community and school. Adaptive behaviour has been defined as the '*performance of daily activities required for personal and social sufficiency*' (Sparrow et al., 2005, pg. 6).

The Vineland Adaptive Behaviour Scales-Second Edition (Vineland-II) is a standardised, norm-referenced evaluation of adaptive behaviour of children and adolescents. The scales measure adaptive behaviour in four domains; 'communication (expressive, receptive and written)', 'daily living skills' (personal, domestic, community), 'social skills and relationships' (interpersonal relationships, play and leisure time, coping skills) and 'physical activity' (fine, gross). The Vineland-II also includes an optional 'Maladaptive Behaviour Index' with 'Internalising' and 'Externalising' subscales.

The Vineland-II Parent/Caregiver rating form used in this study was standardized using a nationally representative American sample of 3,695 individuals from birth to 90 years. Although this measure was standardised on an American population, it has also been used in a number of UK studies (Charman, Howlin, Berry & Prince, 2004; Martin, Bibby, Mudford & Eikeseth, 2003; Pine, Luby, Abacchi and Constantino; 2006) and reported to be a good measure of adaptive behaviour.

3.5.1.3 The Strengths and Difficulties Questionnaire (SDQ)

Matson (2007) highlights the importance of assessing challenging behaviour in children with autism as such behaviour is common in this population of children and can have negative effects on the family as well as educational placement. Using scales such as the Vineland-II and the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) therefore helps to provide information on these behaviours at both time points.

The SDQ is a brief behavioural screening questionnaire that provides coverage of children and young people's behaviours, emotions and relationships. It asks about 25 attributes, some positive and some negative. The 25 items are divided between five scales of five items each generating scores for: Conduct Problems,

Inattention/Hyperactivity, Emotional Symptoms, Peer Problems and Prosocial behaviour. All scales but the last are summed to generate a Total Difficulties Score. The items are in the form of brief statements about the child, and the parents and/or teachers are asked to rate behavioural observations on a three-point scale with the responses 'Not true', 'Somewhat true' and 'Certainly true.'

The original SDQ included children from 4-16 years old, but has now been modified to include 3-4 year olds. Goodman (2001) describes the psychometric properties of the SDQ and concludes that the reliability and validity of the SDQ make it "*a useful brief measure of the adjustment and psychopathology of children and adolescents*" (p.1). However, the evaluations of the instrument do not take into account modifications that were made for the youngest age group. It, therefore, appears that the modified version of the SDQ has, as of yet, not been psychometrically evaluated. The researcher has continued to include this measure in the current study in order to keep within the National Development & Research (D&R) in Educational Psychology's requirements for specific measures being used under the theme 'Identifying Effective Intervention Strategies for Children and Young People with Autistic Spectrum Disorders.'

3.5.1.4 The British Ability Scales – Second Edition (BAS-II)

The BAS-II was selected in order to objectively measure the children's cognitive abilities. Matson (2007), Marwick, et al. (2005) and Jordan, et al. (1998) highlight the importance of using standardised measures of cognitive ability in autism research. Information on cognitive abilities could be gathered through observations and parent interviews, but it was decided that in using a standardised psychometric assessment observer effects could be reduced. The Early Years Lower Level Core Scales, consisting of 4 subtests, were used. The BAS-II provides finer detail than just an 'IQ'

score and the individual scales are sufficiently reliable to provide separate scores on verbal and non-verbal cognitive abilities. In addition, this measure provides age equivalent scores for each subtest used (Elliott et al., 1997).

Although a variety of cognitive tests are available for assessment in the pre-school years, these have been developed primarily for children whose developmental progress follows the 'normal' stages. They are not designed for children whose development is markedly delayed or follows an atypical trajectory, which might be the case in individuals with autism. However, the BAS-II has been used in a number of UK studies in order to assess the development of cognitive functioning in children with autism following some type of intervention (Reed, Osborne, Corners, 2010; Keen & ward, 2004; Martin, Bibby, Mudford, Eikeseth, 2003). It has also been highlighted by Martin et al. (2003) that assessments such as the BAS-II be used with this population of children more often in the UK in order to allow an objective evaluation of their progress over time as the BAS-II covers the age range of 2.5 years to 18 years.

3.5.2 Qualitative Data Collection

Unstructured observation of five of the six children in the study took place at both time points. One child, Oscar, was only observed at the time of initial data collection as his mother did not give consent for him to be observed at the time of secondary data collection. Semi-structured interviews were conducted with five of the six children's parents at the time of secondary data collection. Oscar's mother did not give consent to be interviewed.

3.5.2.1 Informal Observations

Given that three of the measures were dependent on report by the carer or parent, it was decided that further exploration through observation of the children in either the pre-school or home setting would be carried out prior to the EarlyBird group of parents starting the EarlyBird Programme, and again approximately six months after initial data collection. Structured observation was initially going to be used as it is described by Robson (2002) as a good way of quantifying behaviour by taking a detached, 'pure observer' stance, therefore, reducing observer subjectivity. When piloting this method it was agreed that it did provide an overall observation of certain aspects of the child's daily functioning, however, the essence of their interactions and behaviour could not be captured in this way. Informal observation, in which qualitative data were gathered through the use of a 'narrative' was, therefore, employed as an alternative. Observation notes were collected for each child under the categories: Social Interaction, Communication (expressive and receptive language skills), Play, Independence, Attention/Concentration and Overall Behaviour (Appendix 11). The researcher observed the children at the two time points for a period of 45 minutes each (90 minutes in total for each child). Although these observations were only a snapshot in time, the researcher could use the 'narratives' to clarify and highlight observable and reported changes in the children over the study time period.

3.5.2.2 Semi-Structured interviews

The semi-structured interview schedules were created using a sequential mixed models design in which conclusions that were made on the basis of the first strand of questionnaires (EarlyBird questionnaires) led to the formulation of questions for the next strand (Mertens, 2005). A feedback questionnaire, created by the EarlyBird Programme directors, was completed at the end of the programme (Post-Programme Questionnaire) (Appendix 6) by the EarlyBird group of parents. The questionnaires assessed parental rating of outcomes, changes in themselves or their child, what they

have learnt on the programme and what they would tell other parents about the programme. Parents were also asked to comment on their satisfaction with the various components of the EarlyBird Programme. This questionnaire is a generic questionnaire that is completed by all parents who take part in the programme throughout the UK. Unfortunately, the programme trainers posted these to parents and reported that they did not receive many responses back from parents. Additionally, the questionnaire consists of many closed questions, and therefore, where the responses from parents were returned they were insufficient to gain any meaningful data.

The EarlyBird group of parents gave consent for the information to be shared with the researcher for the purposes of this study. The answers that parents in the EarlyBird group provided on the EarlyBird questionnaire were explored. Where further clarification or expansion on answers that parents had provided was required, the researcher included these questions in the semi-structured interview schedules. The questions were linked to the research questions to be explored as well as relevant literature. Major questions were developed which were then followed by a sequence of sub-questions for further probing to help participants develop the richness of their answers if necessary.

The development of the questions that only the non-EarlyBird group of parents were required to answer (questions 13-15) were based on their reasons for not taking part in the programme. The difficulty with recruiting participants to take part in the study had not been foreseen by the researcher, and therefore this became one of the research questions. This group of parents then answered the same questions that had been developed for the EarlyBird group of parents, apart from questions 8-12 which focussed specifically on the EarlyBird Programme, which this group of parents had not taken part in.

The choice of semi-structured rather than structured interviews was due to the need for sufficient flexibility to approach respondents differently, if need be, while still covering the same areas of data collection. Semi-structured interviews are widely used in qualitative research and believed to be a particularly appropriate method for exploratory studies (Willig, 2001). Additionally, the researcher needed to be aware that a balance was required within the interview questions used in order to effectively investigate the research questions, whilst also allowing novel issues to emerge and be explored. As Patton (2002) and Rutter (2005) note, a semi-structured interview format allows this balance to be achieved. Additionally, this format allows the interviewer to follow the respondent's interests and concerns in a free flowing conversation in which the ordering of questions is less important. In other words, the method is very responsive to the individual experiences of participants (Smith, 1996).

In order to ensure that the questions were appropriate in the context of the study, the interview questions were taken to supervision with the researcher's tutors in order to identify any ambiguities or overly sensitive language that might be deemed as inappropriate. Secondly, they were piloted with two Educational Psychologists. Additionally, two parents who were not taking part in the study, but have children with autism, agreed to be interviewed for the purpose of piloting the interviews, but not for analysis. The piloting was aimed at identifying ambiguities, helping to clarify the wording of questions and permitting early detection of necessary additions or omissions.

After the piloting process semi-structured interviews took place with five of the six parents in the study (All three from the EarlyBird group of parents and two from the non-EarlyBird group of parents), as one parent did not give consent to be interviewed. The interviews lasted between 45 minutes and 1 hour. All interviews were recorded using a digital voice recorder, and notes were jotted down by the researcher whilst the

interviews were taking place. After each interview the information was transferred to a computer data base and re-named according to the given pseudonym of the parent's child. The interviews were then transcribed by the researcher and thematically analysed.

Table 5 shows the questions that were answered by each group of parents in the study. Oscar's mother did not give consent to be interviewed, therefore the questions were only asked to five of the six parents. Parents from both groups were asked twenty-one identical core questions (Questions 1 -7 & 16-29). The EarlyBird group of parents were asked five additional questions that specifically focussed on the EarlyBird Programme (Questions 8-12); the non-EarlyBird group of parents were not asked these questions. The non-EarlyBird group of parents were asked three additional questions that focussed on their reasons for not participating in the EarlyBird Programme (Questions 13-15); the EarlyBird group of parents were not asked these questions (Appendix 7).

Question number	Participants
1-7	5 children's parents
8-12	Jack, Christopher and Rory's parents (EB group of parents)
13-15	William and Matthew's parents (non-EB group of parents)
16-29	5 children's parents

Table 5: Interview Questions

3.6 SUMMARY OF PROCEDURE

The table below presents a summary of the procedure that was followed in the current study

Procedure	Description	Participants
1. Telephone Contact	Where parents agreed to take part their contact information was shared with the researcher and parents were telephoned so that further explanation of the study could be given.	All 6 children's parents
2. Consent	Once parents had given verbal consent, the initial information, personal data collection sheet and consent forms were posted to the parents. A self-addressed envelope was included so that parents could return the information via post.	All 6 children
3. Initial Data Collection	Once the consent forms and personal data collection sheets were returned to the researcher, the Vineland II, SDQ and GARS-2 questionnaires were posted to the parents and dates were arranged for the researcher to conduct a formal cognitive assessment of the child as well as observe them in the pre-school or home environment. The researcher arranged to collect the completed questionnaires at this time.	All 6 children
4. Three Month EarlyBird Programme	The three month EarlyBird Programme was completed by EarlyBird group of parents. Children continued to access school as usual.	Jack, Christopher and Rory's parents (EB group of parents)
4. No formal parental intervention	Parents did not seek alternative intervention. Children continued to access pre-school as usual.	Oscar, William and Matthew's parents (non-EB group of parents)
5. Six-Month Follow Up	Six months after the initial data had been collected all parents were sent new copies of the Vineland II, SDQ and GARS-2 questionnaires. Dates were arranged for parents to take part in semi-structured interviews and for the researcher to observe each child and conduct the Early Years BAS-II in the pre-school or home once again	All 6 children and their parents. Only 5 of the 6 parents consented to interviews and secondary observations of their children.

Table 6: Procedure

3.8 SUMMARY

This study has taken a mixed methods approach utilising quantitative questionnaires and standardised assessment, semi-structured qualitative interviews and informal observations to explore individual patterns of development in aspects of cognitive functioning, communication and language skills, social interaction and adaptive behaviour in a group of children in the period immediately following a diagnosis of autism. Additionally, the experiences of these children's parents have also been explored through the utilisation of semi-structured interviews. The following chapter outlines the results of the study.

CHAPTER 4

RESULTS

This chapter aims to answer the research questions posed by presenting both the quantitative analysis of the assessment and questionnaire data, which were collected at both time points, the qualitative analysis of the informal observations of the children which were carried out at both time points and the qualitative analysis of the semi-structured interviews, which were conducted at the second time point.

Individual case narratives for each of the six children are presented with data from the standardised questionnaires and assessments and the informal observations. In addition, a section is included which covers cross-case analysis and results.

4.1 INDIVIDUAL CASE DATA

4.1.1 Analysis

Two of the three questionnaires, namely the Vineland-II and GARS-2, were scored by hand using the instructions provided in the accompanying assessment manuals. The SDQ was scored on the computer using the online programme provided. A psychology assistant within the Educational Psychology Service also scored a total of 5 of the questionnaires to check inter-assessor reliability of the scoring of the measures. There was 100% agreement that the questionnaires were scored correctly. The results of the Early Years BAS-II were scored by hand and a selection of these were input into a computer scoring system and re-scored to ensure that the results were correct. The quantitative data were then input into an Excel database for each child where the initial data and secondary data for each measure used could be compared over the two time

points. Raw scores, percentile scores and age equivalent scores for the children were calculated for each data set.

It is recognised that data obtained from such a small and heterogeneous sample cannot be generalised to the main population. Nevertheless, the results of the quantitative descriptive data are indicative of changes occurring in the six children over the time period of the study. When combined with qualitative data from observation and parent interviews these provide an aggregate profile of individual development from which tentative conclusions can be made.

The scales that relate directly to research question 1 are included in the individual case narratives for each child. Specifically, these are:

- 1. Can we measure the individual patterns of development, and the factors that appear to be important in encouraging any measured development, of a group of pre-school children with autism in aspects of their cognitive functioning, communication and language skills, social interaction and adaptive behaviour?*

4.1.1.1 Vineland Adaptive Behaviour Scales

The Vineland-II uses standard scores to describe the individuals overall functioning (the adaptive behaviour composite) as well as their level of functioning in each of the adaptive behaviour domains. The standard score scale has a mean of 100 and a standard deviation of 15. The adaptive behaviour composite is presented as a percentile score derived from the total score for all 11 sub domains included in the Vineland –II (See Appendix 10 for further detail). The child's adaptive level can be described as 'Adequate' (Average) (Standard Score 86-114), 'Moderately Low' (Standard Score 71-85) or 'Low' (Standard Score 70 & below).

Additionally, age equivalent scores (in months) are provided which indicate the age at which the average person in the population performs at the same level as the individual being assessed. For example, an age equivalent of 4 years 5 months (53 months) on the Receptive Subdomain indicates that the individual's raw score corresponds to the average raw score for individuals aged 4 years 5 months in the standardisation sample (Sparrow et al., 2005). It would be expected that a child would make as many months of progress as the time between the initial data collection and secondary data collection. So, if a child is assessed using the Vineland-II over two time points it is expected that, for example, if there was a 7 month time period between assessments that they would make 7 months progress if compared to a 'typically' developing population of children. However, it cannot be assumed that children with autism would follow a 'typical' developmental trajectory. In this study, where the words 'greater gains' are used, this refers to the progress in months in excess of the time that has passed in months between the two time points.

4.1.1.2 Gilliam Autism Rating Scale

The GARS-2 data for the children provides an Autism Index score which is calculated by first calculating the raw scores of each subscale and then converting them into derived standard scores. It has a mean of 100 and a standard deviation of 15. The derived standard scores for each subscale have a mean of 10 and a standard deviation of 3. Scores of 85 or higher on the Autism Index indicate that an individual is 'Very Likely' to have autism (VL). Scores of 70 to 84 indicate that an individual 'Possibly' has autism (P), and any score of 69 or less suggests that it is 'Unlikely' that the individual has autism (U). The data for each child is presented for both time points. A decrease in a score on any of the subscales of the GARS-2 is positive, as the lower a child's score is on the subscales the less 'severe' their difficulties are in the areas measured.

4.1.1.3 British Ability Scales – Early Years Core Scales

The data for the BAS-II scales are presented for five of the six children. Not all children have results that can be compared over the two time points due to Oscar refusing to cooperate with the researcher at both time points, and Matthew refusing to cooperate with the researcher during initial data collection. The scores obtained from the individual tests on the BAS-II have been combined to give a General Conceptual Ability Score (GCA). An average GCA score is between 90 and 110. Percentiles between 25 and 75 are in the average range, with 50 being the exact average score.

4.1.1.4 The Strengths and Difficulties Questionnaire

The scores on the SDQ are grouped into four bands so that in the general population about 80% of children score 'close to average', 10% score 'slightly raised', 5% score 'high' and 5% score 'very high'. The exception is the scale for kind and helpful behaviour, where 'slightly low', 'low' and 'very low' are used.

In this study the SDQ was not sensitive enough to show changes over the study time period for all the children who took part in the study. There was an additional problem with utilising this measure, which at the time of inclusion in the study had not been considered. All the children in the study changed educational placements during the time period of the study, and therefore, teacher ratings could not be gathered and compared.

4.1.2 Results

The following section presents the results from the analysis of the quantitative and qualitative data that were collected at the two time points. Due to the design of the study each child's data were analysed in two ways:

- Firstly, the data were analysed individually in order to explore where each child had made the greatest developmental gains over the study time period (Appendix 10).
- Secondly, cross-case analyses of the data took place and are presented for all the children in order to explore trends arising from the data where the children have either made expected patterns of development, or exceeded what would be expected, if compared to a 'typically' developing population of children.

Some quotations from the semi-structured interviews that relate to each child are included in the case narratives in order to answer research question 4, specifically:

- *What are the views of parents participating and not participating in the EarlyBird Programme on:*
 - *Perceived gains in their child's development?*

4.1.3 Individual Case Narratives

The data from the individual standardised questionnaires and the BAS-II are presented in table form for each child. Additionally, some quotations from the interview data have been incorporated into the narratives in order to highlight changes over the study time period that were noted by the children's parents.

A section has also been included for each child which highlights changes that were noted in the children by the researcher during the initial and secondary informal behavioural observations.

4.1.3.1 Jack

4.1.3.1.1 Informal Behavioural Observations

During the initial observation Jack was 4 years 5 months and attending a mainstream pre-school. Jack's expressive language was difficult to understand, but he clearly tried to communicate with staff through eye contact, gesture and some single words. Jack was able to follow the routine at school and responded to instructions where his attention was gained by the staff using his first name. On the playground Jack was very active and was running around the periphery with some other boys. He did not tend to engage with any of the other children verbally but was noticed to be smiling whilst running around. In the pre-school Jack flitted from one activity to another. He did not engage with any of the toys that required imaginative play, for example the doll's house and kitchen set. He preferred to play with the toy cars and some Lego bricks. Jack did not tend to engage with other children. He tended to ignore their presence and when children came into his space he moved away.

During the secondary observation eight months later Jack was attending a mainstream primary school. He was working closely with a teaching assistant during observation whilst engaging in table top work. He worked well and was heard talking in fuller sentences and engaging in to and fro conversation with the adult. His attention span during the table top activities was good and with support he maintained attention for 15 minutes before going to play. During play he engaged actively with the other children and joined in with a game where the children were pretending to be running a post office. Jack appeared confused about the rules of play, but still joined in where he could. After 20 minutes Jack moved away from the group and his play became more solitary. He found some toy cars which he played with quietly in the corner. He

responded to the teaching assistant and joined her back at the table to work when she requested.

4.1.3.1.2 Vineland Adaptive Behaviour Scales

					CHRONOLOGICAL AGE				53	61	8
VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT (Months)		DIFF
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
COMMUNICATION					67	76	6	5			
Receptive	20	32	9	14					19	55	36
Expressive	50	53	9	9					27	29	2
Written	2	4	11	10					29	37	8
SOCIALISATION					66	74	1	4			
Interpersonal Relationships	32	32	10	9					22	22	0
Play and Leisure Time	8	25	7	10					9	31	22
Coping Skills	10	19	10	12					25	40	15
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2					
	67	72	1	3	Low	M.Low					

Table 7: Initial and Secondary Vineland-II results - Jack

There was an 8 month time period between the initial data collection and secondary data collection time points for Jack. Over this period Jack's greatest gains were in the areas of 'Receptive' language skills, where he made a gain of 36 months, 'Play and Leisure Time', where he made a gain of 22 months and 'Coping Skills', where he made a gain of 15 months. This data is supported by observations where his play was observed to be both more imaginative, as well as less solitary at the time of secondary observation. He also appeared to show more enjoyment engaging with other children at the time of secondary observation. However, his expressive language skills also appeared to have improved when observing him, although this is not reflected on his scores on the Vineland-II.

Jack's scores on the 'Communication' and 'Socialisation' adaptive behaviour domains increased by 10 points and 8 points respectively over the study time period. Jack's adaptive behaviour composite standard score summarises his overall level of adaptive functioning. His score changed from 67 to 72 at the time of secondary data collection. This meant that Jack's adaptive behaviour level changed in a positive direction, from being classified as 'Low' to 'Moderately Low' over the time period of the study.

4.1.3.1.3 Gilliam Autism Rating Scale

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	4	2	4	3	2	1
Communication	17	3	9	4	9	2
Social Interaction	7	5	4	3	1	1
Autism Index			72	57	3	<1

Table 8: Initial and Secondary GARS 2 results - Jack

Jack's Autism Index score changed by 15 points in the 8 month time period. At the time of initial data collection he was classified as 'Possibly' having autism with a Standard Score of 72 (3rd percentile). At follow up his Standard Score had reduced to 57 with a percentile score of <1, classifying him as 'Unlikely' to receive a diagnosis of autism. It appears from the individual scales on the GARS-2 that his score on the 'Communication' scale changed the most, with his Standard Score differing by 5 points (changing from 9 to 4) and his percentile score decreasing by 7%, from 9% to 2%. This change in his communication was also reported on the Vineland-II and is supported by observational data and verbal reports from his mother.

4.1.3.1.4 British Ability Scales Second Edition– Early Years Core Scales

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT			GCA	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2		TIME 1	TIME 2
Block Building	57	57	30	20	2	1	<2.6	<2.6	Sscore	61	66
Verbal Comprehension	77	88	31	32	3	4	<2.6	<2.6	%ILE	0.5	1
Picture Similarities	10	53	20	36	1	8	<2.6	<2.6			
Naming Vocabulary	63	83	33	37	4	10	<2.6	<2.6			

Table 9: Initial and Secondary BAS-II results - Jack

Jack achieved a General Conceptual Ability Standard Score (GCA) of 61 at the time of initial data collection. This score would have placed him within the 'Very Low' range for cognitive ability. His Standard Score increased by 5 points after the 8 month time period, although he remained within the 'Very Low' range. He made the greatest increases in 'Naming Vocabulary' where his percentile score changed by 6%, from 4 to 10, and 'Picture Similarities' where his percentile score increased by 7%, from 1 to 8. The change in his spoken vocabulary was noted by the researcher during the secondary observation, although it was not reported on the Vineland-II. Nevertheless, this could have impacted on his score in this subtest. Jack's increased attention skills could also have impacted on his scores as it was clear from the secondary observation that his ability to maintain attention and sit at a table and engage in an activity with an adult had improved. His score on the 'Verbal Comprehension' subtest increased, which could reflect improvement in his receptive language skills, as reported on the Vineland-II.

4.1.3.1.5 Strengths and Difficulties Questionnaire

The SDQ was completed by Jack's mother at the two time points. The SDQ data results for Jack were as follows:

SDQ Scales	Initial Data Collection (TIME 1)	Secondary data Collection (TIME 2)
Overall stress	Slightly raised	Slightly raised
Emotional distress	Close to average	Close to average
Behavioural difficulties	Close to average	Slightly raised
Hyperactivity and attentional difficulties	Very high	High

Difficulties getting along with other children	Slightly raised	Slightly raised
Kind and helpful behaviour	Low	Low
Impact of any difficulties on the child's life	High	High

Table 10: Initial and Secondary SDQ results - Jack

The scales that Jack made changes in were the 'Behavioural Difficulties' scale, where there was a change from his behaviour being to 'close to average' to 'slightly raised,' which is a change in a negative direction, and the 'Hyperactivity and Attentional Difficulties' scale, which changed from 'very high' to 'high,' a change in a positive direction. The change in his behaviour is supported by interview data from his mother where she stated that,

"Behaviour wise he is more defiant than he was, he will say no and has preferences of what he would like to wear now."

Although this appears to be a negative change, his mother did not report it as this. She considered that the change in his score on this scale could be due to him wanting to become more independent and therefore being more 'defiant' and insisting on doing things for himself,

"he wants to be more independent, definitely."

The researcher also noted improvements in his attention span and hyperactivity, which was scored on the SDQ, as well as his ability to interact with other children at the time of secondary observation, although his score on the SDQ in this area remained the same over the two time points.

4.1.3.1.6 Summary of Case-Narrative

- Overall Jack made greater age equivalent gains on the Vineland II in his 'Receptive' language (36 months), 'Play and Leisure Time' (22 months) and 'Coping Skills (15 months) scores in the 8 month time period. His overall level of

adaptive functioning changed in a positive direction, from being classified as 'Low' to 'Moderately Low' during the time period of the study.

- On the GARS-2 Jack's Autism Index score decreased and he therefore went from being classified as 'Possibly' having autism, to 'Unlikely' to have autism.
- Jack's GCA standard score on the BAS-II remained within the 'Very Low' range for cognitive abilities, although his scores on both the 'Picture Similarities' and 'Naming Vocabulary' subtests increased.
- His SDQ scores showed improvement in the assessment of hyperactivity and attention difficulties. However, his score for 'behaviour difficulties' was more negative on follow up. These changes were also reported verbally by his mother during the semi-structured interview and the positive change in his hyperactivity and attention levels was highlighted by the researcher at the time of secondary observation.
- The change in his hyperactivity and attention levels was supported by observational data where it was recorded at the time of initial data collection that Jack flitted from one activity to another and did not maintain attention for more than a few seconds. At the time of secondary observation, on the other hand, Jack was able to sit at the table and engage with table-top activities, which he was unable (or unwilling) to do at the time of initial data collection. His ability to engage with toys was greater at the time of secondary observation where Jack played with the pretend post office for more than 20 minutes without adult intervention. The researcher did not observe an increase in oppositional behaviour, or what his mother had termed 'defiant' behaviour at the time of secondary observation.

4.1.3.2 Christopher

4.1.3.2.1 Informal Behavioural Observations

Christopher was 3 years 11 months at the time of initial observation. During the observation at home Christopher was very active and talkative. His expressive language appeared to be age appropriate and it appeared that he had good vocabulary knowledge. It was difficult to engage with him as he talked about his own interests and was flitting from one part of the house to another. He was very excited to show the researcher parts of the house, but did not respond to questions from the researcher. He was unable to engage in 'to and fro' conversation. His activity levels were very high and he was climbing on the furniture, he needed to be removed from the tables and counters frequently. His sister was present during the observation and he was quite rough and aggressive with her. He pushed her over on a number of occasions, took toys from her and shouted in her face. He made no observable response when she started to cry. He did not respond to adult direction and walked away when given verbal instructions. His attention to toys and activities was fleeting and he went from one toy to another, emptied boxes of toys on the floor and did not actively engage with any of the objects.

At the time of secondary observation 8 months later Christopher sat with the researcher for 5 minutes and talked about a fireworks display that he had been to. He was interested in the researcher's view point and asked some questions about the researcher's preference for certain fireworks and whether the researcher had recently been to any displays. His activity levels were high, although he was able to sit and look through some books and talk about them in some detail. He did not climb on the furniture. He spoke to the researcher about his little sister and introduced her by name. He kissed his sister on the cheek and took her by the hand to the kitchen for lunch time. He engaged with a train set for 10 minutes quietly by himself, whilst the researcher

watched, and after this time invited the researcher to join in. He gave the researcher clear verbal instructions about the rules of the game.

4.1.3.2.2 Vineland Adaptive Behaviour Scales

										CHRONOLOGICAL AGE		
										47	55	8
VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF	
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2		
COMMUNICATION					85	100	16	50				
Receptive	20	27	9	12					19	34	15	
Expressive	85	92	16	17					53	66	13	
Written	4	11	13	16					37	58	21	
SOCIALISATION					72	75	3	5				
Interpersonal Relationships	37	36	11	11					29	28	-1	
Play and Leisure Time	12	19	8	9					25	34	9	
Coping Skills	12	16	11	12					27	34	7	
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL							
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2						
	84	96	14	39	M. Low	Av						

Table 11: Initial and Secondary Vineland-II results - Christopher

The time period between initial data collection and secondary data collection for Christopher was 8 months. Christopher's greatest gains were in the areas of 'Receptive' language skills, where he made a gain of 15 months, 'Expressive' language skills, where he made a gain of 13 months and 'Play and Leisure Time,' where he made a gain of 9 months. There was also a reported increase in his 'Written' communication, where he made a gain of 21 months. The reported gains in his communication skills were also noted at the time of secondary observation, specifically his ability to engage in conversation with an adult. Additionally, his play skills had improved and at the time of secondary observation he engaged with some toys, which he had not done before.

Christopher made an increase of 34% on the 'Communication' Domain. His percentile score increased from 16 to 50 at the time of secondary data collection. His standard score for this domain increased by 15 points (from 85 at initial data collection to 100 at the time of secondary data collection). On the other hand, his standard score on the 'Socialisation' domain only increased by 3 points and he moved from being at the 3rd percentile to being at the 5th percentile.

Christopher's adaptive behaviour composite standard score summarises his overall level of adaptive functioning. He achieved a percentile score of 39 at the time of secondary data collection on the adaptive behaviour composite, where he has achieved a score of 14 at the time of initial data collection, meaning that his percentile score increased by 25%. Over the 8 month time period Christopher's adaptive behaviour level changed in a positive direction, from 'Moderately Low' to 'Average.'

4.1.3.2.3 Gilliam Autism Rating Scale

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	18	14	9	8	37	29
Communication	16	8	9	6	37	9
Social Interaction	15	23	7	10	16	50
Autism Index			89	87	23	19

Table 12: Initial and Secondary GARS-2 results - Christopher

Christopher's Autism Index Standard Score decreased by 2 points and his percentile score decreased by 4%. At the time of initial data collection Christopher was classified as being 'Very Likely' to have autism. His classification did not change over the time period of the study. It appears from the individual scales on the GARS that his score on

the 'Communication' scale reduced by 28% (from being at the 39th percentile at the time of initial data collection to the 9th percentile at the second time point). This reduction is positive as it shows that his communication has improved. This improvement was reported on the Vineland-II and also noted in observations. Specifically this appears to refer to his ability to engage in some 'to and fro' conversation, as well as listen to another person's point of view. His standard score on the 'Stereotyped Behaviour' subscale reduced by 1 point, and he moved from being at the 37th percentile to being at the 29th percentile. His percentile score on the 'Social Interaction' subscale changed from 16 at the first time point to 50 at the second time point, an increase of 34%. It is unclear whether this increase is in fact indicative of his social behaviour as he was observed in the home environment and not at school. It was reported by his mother that his play does tend to be solitary, and because of a history of aggressive behaviour other children do not tend to engage in play with him.

4.1.3.2.4 British Ability Scales Second Edition – Early Years Core Scales

EARLY YEARS BAS-II LOWER LEVEL CORE	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT			GCA	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2		TIME 1	TIME 2
Block Building	57	77	33	34	4	5	<2.6	2.10	Sscore	98	103
Verbal Comprehension	102	113	47	48	38	42	3.4	4.4	%ILE	45	58
Picture Similarities	59	57	46	40	34	16	3.1	2.10			
Naming Vocabulary	107	141	67	80	96	99	5.7	8+			

Table 13: Initial and Secondary BAS-II results - Christopher

Christopher achieved a General Conceptual Ability Standard Score (GCA) of 98 at the time of initial data collection. This score would have placed him within the 'Average' range for cognitive ability. His standard score increased by 5 points in the 8 month time period, with an increase of 13% in his GCA percentile score. His score at the

second time point would still place him within the 'Average' range. His ability to sit for longer periods of time with the researcher and maintain attention may have impacted on his score. He made the greatest gains in the 'Verbal Comprehension' subtest, where his percentile score increased by 4% (from 38 to 42). His score on the 'Picture Similarities' subtest reduced by 18%, from the 34th percentile to the 16th percentile. However, the reduction in the 'Picture Similarities' score appears to be due to Christopher constantly asking why the two pictures went together and it appeared that he was trying to be overly logical about the reasons that they would go together, or not go together. He therefore placed many of them in the wrong place, although could verbally give very good reasons why he had placed them where he had. Christopher's score for the 'Naming Vocabulary' subtest (99th percentile) would place him within the 'Very High' range for his vocabulary knowledge. The researcher observed at both time points that his expressive language skills were very good for a child of his age, although at the first time point he did not actively engage in 'to and fro' conversation.

4.1.3.2.5 Strengths and Difficulties Questionnaire

The SDQ was completed by Christopher's mother at the two time points. The SDQ data results for Christopher were as follows:

SDQ Scales	Initial Data Collection (TIME 1)	Secondary data Collection (TIME 2)
Overall stress	Very high	Very high
Emotional distress	Close to average	Close to average
Behavioural difficulties	Very high	Very high
Hyperactivity and attentional difficulties	Very high	High
Difficulties getting along with other children	Very high	High
Kind and helpful behaviour	Very low	Very low
Impact of any difficulties on the child's life	Very high	Very high

Table 14: Initial and Secondary SDQ results - Christopher

The scales that Christopher made changes in were the 'Hyperactivity and attentional difficulties' scale, which changed from 'very high' to 'high,' and the 'Difficulties getting

along with other children' scale where his score also changed from 'very high' to 'high.'

The changes in his behaviour are supported by interview data from his mother where she stated that,

"I would say that he is listening slightly more, still very excitable and in your face but he can be a lot calmer and he is definitely no threat to another child anymore. We can take him to a playground now."

"He was invited to a party the other day and there was a big difference."

His reduction in hyperactivity and improved attention span was noted by the researcher during the secondary observation. Additionally, the researcher also noted an improvement in how he related to his sister, which was also reported on the SDQ, where his score improved on the 'Difficulties getting along with other children' scale.

4.1.3.2.6 Summary of Case-Narrative

- Overall Christopher made greater age equivalent gains on the Vineland II in his 'Receptive' language (15 months), 'Expressive' language (13 months), 'Written' communication (21 months) and 'Play and Leisure Time' (9 months) scores. His overall level of adaptive functioning changed in a positive direction, from 'Moderately Low' to 'Average' during the time period of the study.
- On the GARS-2 Christopher was classified as 'Very Likely' to have autism at both time points.
- Christopher's GCA standard score on the BAS-II remained within the 'Average' range for cognitive abilities although his scores for the 'Naming Vocabulary' and 'Verbal Comprehension' subtests increased and his score for the 'Picture Similarities' subtest decreased.

- His SDQ scores showed improvement in hyperactivity and attention difficulties and his ability to get along with other children. These improvements were also reported verbally by his mother during the semi-structured interview and were highlighted by the researcher at the time of secondary observation.
- The reported changes in Christopher's behaviour were observed at the time of secondary observation. Christopher was able to play for longer periods of time by himself, as well as engage in some to and fro conversation. Additionally, Christopher was gentler with his sister and showed some empathy towards her, which he had not done during the initial observation.

4.1.3.3 Rory

4.1.3.3.1 Informal Behavioural Observations

Rory was 2 years 10 months at the time of initial observation where he was observed at home. He did not use any spoken language but tended to use gesture to communicate. When he wanted something he would lead the adult towards the item he wanted, or look at it. Rory's play was solitary and he grabbed toys from his brother when he wanted them. He spun the wheels of a car continuously and did not respond to his mother's attempts to engage him in another activity. Rory did not show interest in the adults around him.

At the time of secondary observation six months later Rory's eye contact had increased and he was using some single spoken words. He was able to get his needs met through simple verbal requests, although still led his mother by the hand when he wanted something. He played with his brother in a turn-taking game, where they were stacking bricks to make a tower. He also took it in turns to knock the tower over, and

laughed when this happened. He made eye contact with the researcher and came over to her. He showed interest in her bag as well as the earrings that she was wearing. He responded to some simple spoken instructions from his mother, for example, when she asked him to wash his hands as it was time for a snack he walked to the bathroom independently.

4.1.3.3.2 Vineland Adaptive Behaviour Scales

								CHRONOLOGICAL AGE			34	40	6
VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF		
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2			
COMMUNICATION					61	65	<1	1					
Receptive	8	11	7	6					9	12	3		
Expressive	15	23	8	8					9	16	7		
Written	0	4	/	14					0	37	37		
SOCIALISATION					76	77	5	6					
Interpersonal Relationships	21	26	9	9					7	15	8		
Play and Leisure Time	11	24	10	12					12	30	18		
Coping Skills	12	10	13	12					27	25	-2		
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL								
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2							
	68	82	2	12	Low	M.Low							

Table 15: Initial and Secondary Vineland-II results - Rory

There was a 6 month time period between the initial data collection and secondary data collection time points for Rory. Rory's greatest gains were in the areas of 'Expressive' language skills, where he made a gain of 7 months, 'Interpersonal Relationships,' where he made a gain of 8 months and 'Play and Leisure Time,' where he made a gain of 18 months. His development in these areas was also noted by the researcher at the time of secondary observation. It was reported that he made a gain of 37 months in his 'Written' communication skills. However, when looking at the criteria for scoring on the Vineland-II over the two time periods it appears that at the time of initial data collection

he had not scored at all on this scale, whereas at the time of secondary data collection his mother scored that he 'identifies one or more alphabet letters as letters and distinguishes them from number' and 'identifies at least 10 printed letters of the alphabet.' This new skill that Rory had developed over the time period of the study is reflected as a gain of 37 months on the Vineland-II. Additionally, perhaps his willingness to engage in activities such as painting and drawing, as reported by his mother verbally, has also led to such an unusual increase in his score on this sub domain.

Rory's standard score for the 'Communication' domain increased by only 4 points, despite the very large increase that was seen in his 'Written' skills over the time period of the study. This is perhaps due to the relatively small developments that he made in this domain in other areas. His standard score on the 'Socialisation' domain increased by 1 point.

Rory's adaptive behaviour composite score summarises his overall level of adaptive functioning. He achieved a standard score of 82 at the second time point, compared to his initial score of 68. Rory's adaptive behaviour level changed in a positive direction, from 'Low' to 'Moderately Low' within the time period of the study.

4.1.3.3 Gilliam Autism Rating Scale

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	29	29	13	13	84	84
Communication	36	34	16	16	98	98
Social Interaction	36	31	15	14	93	91
Autism Index			130	128	98	98

Table 16: Initial and Secondary GARS-2 results - Rory

In the 6 month time period Rory's Autism Index standard score reduced by 3 points and he remained at the 98th percentile. At both time points he was classified as being 'Very Likely' to have autism. There were no changes in two of the three subscales. However, his standard score on the 'Social Interaction' subscale reduced by 1 point and his percentile score decreased by 2%, from the 93rd percentile to the 91st percentile. His increased levels of socialisation with both his brother and adults were also observed by the researcher at the time of secondary observation.

4.1.3.3.4 British Ability Scales Second Edition – Early Years Core Scales

EARLY YEARS BAS-II LOWER LEVEL CORE	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT			GCA	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2		TIME 1	TIME 2
Block Building	32	57	34	36	5	8	<2.6	<2.6	Sscore	60	77
Verbal Comprehension	10	57	20	28	1	1	<2.6	<2.6	%ILE	0.4	6
Picture Similarities	17	48	27	42	1	21	<2.6	<2.6			
Naming Vocabulary	37	66	31	42	3	21	<2.6	<2.6			

Table 17: Initial and Secondary BAS-II results - Rory

Rory achieved a General Conceptual Ability standard score (GCA) of 60 at the time of initial data collection. This score would have placed him within the 'Very Low' range for cognitive ability. At the time of secondary data collection his standard score increased by 17 points after the 6 month time period. At the time of secondary data collection his GCA standard score of 77 would place him within the 'Low' range for cognitive ability. His percentile score increased by 5.6%, from him being placed at the 0.4th percentile to the 6th percentile at the time of secondary data collection. He made a percentile gain of 20% on the 'Picture Similarities' subtest, where his score increased from him being placed at the 1st percentile at the first time point to the 21st percentile at the second time point. His score on the 'Naming Vocabulary' subtest increased by 18%. He

moved from the 3rd percentile to the 21st percentile in the 6 month time period. His increased scores on the sub-tests may be due to his increased levels of cooperation that were observed at the time of secondary observation. Additionally, it did appear that his expressive language skills had improved, both on the Vineland-II and during observation, which could have impacted on his 'Naming Vocabulary' score.

4.1.3.3.5 Strengths and Difficulties Questionnaire

The SDQ was completed by Rory's mother at the two time points. The SDQ data results for Rory were as follows:

SDQ Scales	Initial Data Collection (TIME 1)	Secondary data Collection (TIME 2)
Overall stress	Very high	Very high
Emotional distress	Very high	Very high
Behavioural difficulties	Very high	Very high
Hyperactivity and attentional difficulties	Very high	Very high
Difficulties getting along with other children	Very high	Very high
Kind and helpful behaviour	Very low	Very low
Impact of any difficulties on the child's life	Very high	Very high

Table 18: Initial and Secondary SDQ results - Rory

Rory's reported SDQ scores did not change over the six month time period. He scored within the 'very high' range for all of the subscales except 'Kind and helpful' behaviour, where he scored 'very low.' His mother reported that she had not seen large enough changes in his behaviours over the time period of the study in any of the subscales. However, it appears through her verbal reports during interview that his behaviour towards other children had improved as his mother stated,

"He is better with other children, you know more tolerant. He can still be aggressive with his brother, but not as bad as before."

Although there were no changes in the reported scores on the SDQ, the researcher had noted an improvement in his attention span and hyperactivity, as well as his ability to get along with other children at the time of secondary observation.

4.1.3.3.6 Summary of Case-Narrative

- Overall Rory made greater age equivalent gains on the Vineland II in his 'Expressive' language (7 months), 'Interpersonal Relationships' (8 months), 'Play and Leisure Time' (18 months) and 'Written' Communication (37 months) scores. His overall level of adaptive functioning changed in a positive direction, from 'Low' to 'Moderately Low' during the time period of the study.
- On the GARS-2 Rory was classified as 'Very Likely' to have autism at both time points.
- Rory's GCA standard score on the BAS-II increased. He went from being within the 'Very Low' range for cognitive abilities at the time of initial data collection, to being within the 'Low' range at the time of secondary data collection. His scores on all but one of the subtests increased.
- Rory did not show improvement in any of the scales on the SDQ. However, the researcher highlighted changes in his ability to play cooperatively with his brother at the time of secondary observation. During the second observation the researcher reported that he was able to engage in play with his brother, which he had not done before. During the initial observation he had only engaged in solitary play.

4.1.3.4. Oscar

4.1.3.5.1 Informal Behavioural Observations

Oscar was 4 years 3 months when observed at a mainstream pre-school. Oscar was not heard using language to communicate with staff or his peers. He appeared to repeat learnt phrases over and over again. Oscar wandered around the play area, but did not engage with his peers or the adults around him. Oscar found a toy bus and pushed it up and down the carpet with his head on the floor for 20 minutes. When adults attempted to engage him in alternative activities he stood up and wandered off. He appear to listen to some songs that were sung as part of a group session, although watched the group from further away and left the room after a few minutes.

There is no secondary observation data for Oscar due to his mother not consenting to him being observed at the second time point.

4.1.3.4.2 Vineland Adaptive Behaviour Scales

					CHRONOLOGICAL AGE				52	59	7
VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
COMMUNICATION					47	65	<1	1			
Receptive	7	7	4	7					8	14	6
Expressive	11	8	4	8					9	25	16
Written	4	13	12	13					37	51	14
SOCIALISATION					70	61	2	<1			
Interpersonal Relationships	16	20	6	7					5	7	2
Play and Leisure Time	4	6	6	6					4	7	3
Coping Skills	2	12	7	11					4	27	23
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						

	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
	57	60	<1	<1	Low	Low

Table 19: Initial and Secondary Vineland-II results - Oscar

There was a 7 month time period between the initial data collection and secondary data collection for Oscar. Oscar's greatest gains were in the areas of 'Expressive' language skills, where he made a gain of 16 months, and 'Coping' skills, where he made a gain of 23 months. His 'Written' skills were also reported to have increased by 14 months. The increase in his coping skills could be a result of his increased independence as reported by his mother, as well as the fact that he was able to attend his new primary mainstream school by himself, which he could not do before. The increase in his 'Written' skills could be due to his ability to recognise some letters of the alphabet, as well as write his name as reported by his mother on the Vineland-II form.

Oscar made an increase of 18 points on the 'Communication' domain where his standard score increased from 47 to 65. On the other hand, his standard score on the 'Socialisation' domain decreased by 9 points, from 70 to 61. It is unclear what this decrease would look like for Oscar as he was not observed to be socialising at all during the initial observation. Unfortunately, there are no secondary observation notes due to his mother not consenting to him being observed at the second time point. This would have been useful in order to help clarify the possible reasons for a reported decrease in his score on this domain. His adaptive behaviour composite standard score increased by 2 points, from 57 at the stage of initial data collection to 60 at the stage of secondary data collection. This means that his adaptive level continued to be classified as 'Low' at the second time point.

4.1.3.4.3 Gilliam Autism Rating Scale

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	21	28	10	13	50	84
Communication	47	34	19	16	99	98
Social Interaction	27	25	12	11	75	63
Autism Index			124	122	95	93

Table 20: Initial and Secondary GARS-II results - Oscar

In the 7 month time period Oscar's Autism Index standard score reduced by 2 points. His percentile score on the Autism Index reduced by 2%, from the 95th percentile to the 93rd percentile. At both time points Oscar was classified as 'Very Likely' to have autism. There were noticeable changes in two of the three subscales, namely 'Stereotyped Behaviour' (50th percentile to the 84th percentile – an increase of 34%) and 'Social Interaction' (75th percentile to the 63rd percentile – a decrease of 12%). Due to not having consent to observe Oscar at both time points it is unclear whether these scores are truly indicative of changes in his behaviour. However, it is clear that his score on the Social Interaction scale of the GARS indicates an improvement in social interaction, whereas his score on the Socialisation domain of the Vineland-II indicates a decrease in these skills. It would have been useful to have had the opportunity to observe Oscar in order to help clarify this discrepancy.

4.1.3.4.4 British Ability Scales Second Edition – Early Years Core Scales

Oscar would not cooperate with the researcher on two occasions when attempts were made to assess his cognitive ability using the BAS-II. Therefore, there are no BAS-II scores for this child.

4.1.3.4.5 Strengths and Difficulties Questionnaire

The SDQ was completed by Oscar's mother at the two time points. The SDQ data results for Oscar were as follows:

SDQ Scales	Initial Data Collection (TIME 1)	Secondary data Collection (TIME 2)
Overall stress	Very high	Very high
Emotional distress	High	Very high
Behavioural difficulties	High	Close to average
Hyperactivity and attentional difficulties	Slightly raised	Slightly raised
Difficulties getting along with other children	Very high	Very high
Kind and helpful behaviour	Very low	Very low
Impact of any difficulties on the child's life	Very high	Very high

Table 21: Initial and Secondary SDQ results - Oscar

The only subscale where there was a change for Oscar was the 'Behavioural difficulties' scale. His mother reported on the Vineland II that he was able to attend school without her, which he could not do before. This increase in independence and coping skills may have impacted on his score on the SDQ on this scale.

4.1.3.4.6 Summary of Case-Narrative

- Overall Oscar made greater gains on the Vineland II in his 'Expressive' language (16 months), 'Coping skills (23 months) and 'Written' communication (14 months) scores. His overall level of adaptive functioning remained 'Low' during the time period of the study.
- On the GARS-2 Oscar was classified as 'Very Likely' to have autism at both time points.
- His SDQ scores showed improvement in the behavioural difficulties subscale. This improvement could be due to his increased independence as reported by his mother.

- Unfortunately BAS-II data, secondary observation data and parental interview data are not available for Oscar.

1.1.3.5 William

4.1.3.5.1 Informal Behavioural Observations

William was 3 years 6 months at the time of initial observation. He was observed in a mainstream pre-school. William was non-verbal, although was using some vocalisations to express enjoyment or dissatisfaction. William was very active and ran from one area to another. He did not maintain attention for long periods of time and his attention was generally fleeting. He appeared to enjoy being with adults and smiled at them, held their hands and at one stage climbed on to the researcher. His eye contact was good and he used eye gaze to communicate when he wanted something. He appeared to have some sensory difficulties as he was constantly attempting to remove his clothing. He did not engage with any of the other children and most of the time did not acknowledge their presence in the room with him.

At the time of secondary observation seven months later William was observed in a special primary school. He was not using verbal language spontaneously to make requests, although did use some symbols and when prompted would pair the spoken word with the picture. He sat with a staff member for 1 minute engaging in a table top activity and then was allowed to go to the play area. He chose a toy, a singing Elmo, which he played with alone for 20 minutes. On a number of occasions another child tried to take the toy from him. He responded with a high pitched scream and attempted to hit the child. He sat for a group singing session, but after 2 minutes started crying

and covering his ears. He was encouraged to remain seated with the aid of a sand timer and reward. After a short time he left the group and went back to his chosen toy.

4.1.3.5.2 Vineland Adaptive Behaviour Scales

								CHRONOLOGICAL AGE			42	49	7
VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF		
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2			
COMMUNICATION					47	42	<1	<1					
Receptive	6	6	3	3					6	6	0		
Expressive	12	16	6	5					8	9	1		
Written	1	0	11	9					25	22	-3		
SOCIALISATION					66	61	1	<1					
Interpersonal Relationships	19	14	7	6					6	4	-2		
Play and Leisure Time	8	6	8	7					9	7	-2		
Coping Skills	11	12	12	11					26	27	1		
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL								
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2							
	62	61	1	<1	Low	Low							

Table 22: Initial and Secondary Vineland-II results - William

There was a 7 month time period between the initial data collection and the secondary data collection time points for William. William did not make a gain in any of the Vineland II subscales. In fact his data shows that he regressed in 3 of the 6 subscales. He made no gains in any of the sub-domains that matched or exceeded the 7 month time period.

William's standard scores on the 'Communication' and 'Socialisation' domains both reduced by 5 points. His adaptive behaviour composite standard score, which summarises his overall level of adaptive functioning, decreased by 1 point at the time of secondary data collection. William's adaptive behaviour level therefore remained 'low.' These changes are supported by observational data where there appeared to be

a decrease in William's social interaction with the adults around him. Additionally, William's sensory difficulties appeared to have increased where he was observed as being more intolerant of noise than he had been at the time of initial observation.

4.1.3.5.3 Gilliam Autism Rating Scale

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	24	33	11	15	63	95
Communication	NV	9	NV	6	NV	9
Social Interaction	24	29	10	12	50	75
Autism Index			133	106	99	65

Table 23: Initial and Secondary GARS-2 results – William

Due to William being non-verbal at the time of initial data collection a score for the 'Communication' subscale could not be gained at that time. An Autism Index Score can still be calculated when this scale is omitted. At the stage of secondary data collection William had started using some expressive language. His mother therefore scored this scale.

In the 7 month time period William's Autism Index standard score reduced by 27 points and his percentile score on the Autism Index reduced by 34%, from the 90th percentile to the 65th percentile. At both time points William was classified as 'Very Likely' to have autism. There were noticeable changes in both of the subscales that were completed for him, namely 'Stereotyped Behaviour' (63rd percentile to the 95th percentile – an increase of 30%) and 'Social Interaction' (50th percentile to the 75th percentile – an increase of 25%). The researcher did not observe an increase in stereotypical behaviours, although there was a noticeable difference in his sensory difficulties. His mother also reported an increase in, what she termed, 'obsessional' behaviour, where he would only play with one toy and would become distressed if this was removed. Perhaps this affected his score in this area. The increase in his 'Social Interaction'

score was supported by observation data where it was highlighted that he was not interacting with his peers or other adults, where he had appeared keen to interact with adults at the time of initial observation. Logically his score on the Autism Index should have increased rather than decreased as two of the subscales that were completed at the stage of initial data collection increased. It appears that the inclusion of the 'Communication' subscale, where he scored at the 9th percentile has affected the overall standard score on the GARS.

4.1.3.5.4 British Ability Scales Second Edition – Early Years Core Scales

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT			GCA	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2		TIME 1	TIME 2
Block Building	10	10	23	20	1	1	<2.6	<2.6	Sscore	59	62
Verbal Comprehension	10	10	20	20	1	1	<2.6	<2.6	%ILE	0.3	0.6
Picture Similarities	36	74	34	56	5	73	<2.6	4.7		NV Composite	
Naming Vocabulary*	51		32		4		<2.6		Sscore	65	81
Naming Vocabulary	10	26	20	20	1	1	<2.6	<2.6	%ILE	1	10
*use of gesture and sign											

Table 24: Initial and Secondary BAS-II results - William

Due to William being non-verbal the Non-Verbal composite score was used instead of the General Conceptual Ability standard score (GCA), which includes a verbal scale. William achieved a standard score at the first time point of 65, which would have placed him within the 'Very Low' range for cognitive ability. At the second time point his standard score increased by 16 points over the 7 month time period. His Non-verbal composite standard score at the time of secondary data collection of 81 would place him within the 'Below Average' range for non-verbal cognitive ability. His percentile score increased by 9%, from him being placed at the 1st percentile to the 10th percentile

at the time of secondary data collection. He made a percentile gain of 68% on the 'Picture Similarities' subtest, where his score increased from him being placed at the 5th percentile at time of initial data collection to the 73rd percentile at the second time point. This unusual increase could be related to William's reduced activity levels and increased attention span as observed by the researcher. During the second administration of the BAS-II William sat at the table and maintained attention throughout the entire assessment, which he had not done before. He was very active at the time of initial observation and was unable to maintain attention for more than a few seconds. At the time of secondary observation he was able to play with one toy for over 20 minutes and tended not to flit between toys or people. He showed less interest in people and perhaps this meant that he was less likely to be distracted at the time of secondary data collection when he was re-assessed.

4.1.3.5.5 Strengths and Difficulties Questionnaire

The SDQ was completed by William's mother at the two time points. The SDQ data results for William were as follows:

SDQ Scales	Initial Data Collection (TIME 1)	Secondary data Collection (TIME 2)
Overall stress	Very high	Very high
Emotional distress	Close to average	Close to average
Behavioural difficulties	Very high	Very high
Hyperactivity and attentional difficulties	Very high	Very high
Difficulties getting along with other children	Very high	Very high
Kind and helpful behaviour	Very low	Very low
Impact of any difficulties on the child's life	Very high	Very high

Table 25: Initial and Secondary SDQ results – William

None of the subscales on the SDQ changed for William over the two time periods. His mother reported that,

We have to plan our day, our life around [child], the autism is family life really. Little one (brother) misses out on so much.

Researcher: Do you think [child's] autism has had any positive effects on the family?

Mother: If I'm honest, no. He's [child's name] and we can't change that. We have to take it one day at a time.

Although his mother reported no changes in William's behaviour on the SDQ during the time period of the study, informal observation of William highlighted that his hyperactivity and attentional difficulties had improved. Additionally, his mother also verbally reported that his levels of emotional distress had increased, which has not been reflected in his SDQ scores.

4.1.3.5.6 Summary of Case-Narrative

- Overall William did not make any improvements in his scores on the Vineland II. No change was seen in his overall level of adaptive functioning, where his level remained 'Low' during the time period of the study.
- On the GARS-2 William was classified as 'Very Likely' to have autism at both time points.
- William's GCA standard score on the BAS-II changed from him being within the 'Very Low' range at time one to him being within the 'Below Average' range at time two. His score on the 'Picture Similarities' subtest increased substantially.
- William did not show improvements in any of the scales on the SDQ. However, the researcher highlighted positive changes in his levels of hyperactivity and attention at the time of secondary observation.
- The researcher highlighted during the secondary observation that William's eye contact and initiation of non-verbal communication with adults had reduced. At the initial stage of data collection William had been more willing to engage in

play as well as be close to an adult. At the time of secondary data collection, on the other hand, he was more solitary and did not show much interest in other people around him. It is unclear why this change had occurred, although it may be as a result of his new school placement and change in the environment and his routine.

4.1.3.6 Matthew

4.1.3.6.1 Informal Behavioural Observations

Matthew was 3 years 4 months at the time of initial observation. He was observed in a mainstream pre-school. Matthew did not appear to be happy to have the researcher present and was repeating 'Lady go' over and over again. After some time he appeared to settle and lost interest in the researcher. Matthew's play was solitary and he enjoyed sitting at a table alone and drawing the solar system. His drawing was very advanced for a child of his age and he knew the names of all the planets, how many moons each planet has and the names of all the moons. He was repeating these to himself throughout the observation. After some time he was encouraged to join the rest of the children. He stood on the sidelines and watched them for a few minutes. He then went back to his drawing. Matthew's expressive language appeared echolalic as he only repeated what others said to him and did not reply when spoken to. He did not talk to adults or other children.

At the time of secondary observation seven months later Matthew was observed in a mainstream pre-school. He was running in the play ground with other children for 10 minutes and then went inside. He found a pretend bed and told the researcher to look at him. He then pretended to get into bed, turn his light off and go to sleep. A little girl came in and joined him. Initially he asked to her to leave, but then he started to jump on the bed with her and they laughed together. They then played a game together

where they took turns to be the 'mummy' and put each other to bed. Matthew engaged with the other child for over 30 minutes.

4.1.3.6.2 Vineland Adaptive Behaviour Scales

								CHRONOLOGICAL AGE			40	47	7
VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF		
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	7		
COMMUNICATION					104	108	61	70					
Receptive	23	26	11	12					22	29	7		
Expressive	66	73	13	14					34	39	5		
Written	26	26	24	24					83	83	0		
SOCIALISATION					74	77	4	6					
Interpersonal Relationships	17	26	7	9					6	15	9		
Play and Leisure Time	10	17	9	10					11	18	7		
Coping Skills	20	17	15	14					41	35	-6		
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL								
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2							
	87	84	19	14	AV	M.Low							

Table 26: Initial and Secondary Vineland-II results - Matthew

There was a 7 month time period between the initial and secondary data collection time points for Matthew. Matthew made a gain in 'Interpersonal Relationships' of 9 months in the 7 month time period. He did not make gains in any other areas that were greater than expected, although his 'Receptive Language' skills and 'Play and Leisure' time developed at the rate that would be expected if compared to a 'typically' developing child over the two time points.

He did not make any gains in 'Written' communication, which appears logical as his age equivalent score on this scale was 43 months more than his true age at the time of initial data collection. It was observed and verbally reported by his mother that Matthew

could draw the solar system and write the names of all the planets and their moons. Although at the time of secondary observation Matthew's expressive language was less echolalic than it had been previously, for example, he was able to answer some simple questions about the activity he was engaging in rather than repeating what was asked, this has not been reflected on his Vineland-II score. Additionally, Matthew was engaging in 'to and fro' conversations with other children, which he had not done during the observation at the stage of initial data collection. This improvement was also highlighted by his mother during the interview where she stated,

"He is not echoing so much. He is more expressive, his vocabulary is much better. He can initiate conversations and the other day said 'see me mummy' which is huge step for him to initiate something. Much more two-way conversation. It is still very fixed on his interests; he can talk about the solar system forever, but he is much more able to try and make a comment on things!"

Matthew's standard scores on the 'Communication' and 'Socialisation' subdomains increased by 4 points and 3 points respectively over the time period of the study. These increases are supported by observational data and verbal reports from his mother. His adaptive behaviour composite standard score summarises his overall level of adaptive functioning. His standard score reduced by 3 points, from 87 to 84 during the time period of the study meaning that his overall level of adaptive behaviour changed in a negative direction, from 'Average' to 'Moderately Low'. Although his Vineland-II scores indicate a change in a negative direction, parental verbal reports and observational data indicate improvements in Matthew's adaptive behaviour over the time period of the study.

4.1.3.6.3 Gilliam Autism Rating Scale

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	13	4	7	4	16	2

Communication	24	12	12	7	75	16
Social Interaction	20	12	9	6	37	9
Autism Index			96	72	39	3

Table 27: Initial and Secondary GARS-2 results - Matthew

In the 7 month time period Matthew's Autism Index standard score reduced by 24 points. His percentile score on the Autism Index reduced by 36%, from the 39th percentile to the 3rd percentile. At the first time point Matthew was classified as 'Very Likely' to have autism, whereas at the second time point he was classified as 'Possibly' having autism. There were noticeable changes in all three of the subscales that were completed for him, namely 'Stereotyped Behaviour' (16th percentile to the 2nd percentile – a decrease of 14%), 'Social Interaction' (75th percentile to the 16th percentile – a decrease of 59%), and 'Communication' (37th percentile to the 9th percentile – a decrease 28%). These changes were also observed by the researcher at the time of secondary observation. Matthew did not repetitively engage in drawing the solar system and was able to interact with another child and take turns in a game. He also used expressive language that was less echolalic than what had been observed at the time of initial observation.

4.1.3.6.4 British Ability Scales Second Edition – Early Years Core Scales

EARLY YEARS BAS-II LOWER LEVEL CORE	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT			GCA	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2		TIME 1	TIME 2
Block Building	REF	68	REF	36	REF	8	REF	<2.6	Sscore	n/a	108
Verbal Comprehension	REF	102	REF	47	REF	38	REF	3.4	%ILE	n/a	70
Picture Similarities	REF	79	REF	63	REF	90	REF	5.4			
Naming Vocabulary	REF	107	REF	67	REF	96	REF	5.7			

Table 28: Initial and Secondary BAS-II results - Matthew

Matthew only completed the British Ability Scales at the time of secondary data collection. At the time of initial data collection Matthew refused to work with the

researcher in order to complete the assessment. Matthew was happy to do this at the second data collection time point. Matthew achieved a General Conceptual Ability standard score (GCA) of 108. This score would place him within the 'Average' range for cognitive ability. His scores on the subscales do appear to be indicative of some of his abilities that were observed. His score on the 'Naming vocabulary' subtest would place him at the 96th percentile. It was clear that his language and vocabulary knowledge were very good for a child of his age, which has been reflected in this score. Additionally, his 'Verbal Comprehension' score is low, which could indicate difficulties with receptive language which were reported on the Vineland II and verbally by his mother.

4.1.3.6.5 Strengths and Difficulties Questionnaire

SDQ Scales	Initial Data Collection (TIME 1)	Secondary data Collection (TIME 2)
Overall stress	Close to average	Close to average
Emotional distress	Close to average	Close to average
Behavioural difficulties	Close to average	Close to average
Hyperactivity and attentional difficulties	Close to average	Close to average
Difficulties getting along with other children	Very high	Slightly raised
Kind and helpful behaviour	Very low	Very low
Impact of any difficulties on the child's life	Very high	Very high

Table 29: Table 8: Initial and Secondary SDQ results - Matthew

Matthew's score on the 'Difficulties getting along with other children scale' changed from 'very high' to 'slightly raised.' His mother reported in the interview that,

Interviewer: Could you describe what [child] was like 6 months ago?

Mother: He was more likely to play on his own; he didn't choose to play with other children, either his own age or even older.

[child] has just started to be able to copy other children's behaviours, he has been copying [brother], but now also in the school playground. He seems more comfortable with other children around him.

Socially, he is much more sociable, which has mainly been due to his older brother more than anything. He's the absolute best therapist!

His improvements in this area were also noted by the researcher during the secondary observation.

4.1.3.6.6 Summary of Case-Narrative

- Overall Matthew made greater age equivalent gains on the Vineland II in his 'Interpersonal Relationships' score (9 months). His overall level of adaptive functioning changed in a negative direction, from 'Average' to 'Moderately Low' during the time period of the study.
- On the GARS-2 Matthew was classified as 'Very Likely' to have autism at the time of initial data collection. His score on the Autism Index reduced at the time of secondary data collection and he was classified as 'Possibly' having autism.
- Matthew's GCA standard score on the BAS-II classified him as being within the 'Average' range for cognitive abilities. There is no initial data available for comparison over the two time points.
- His SDQ scores showed improvement in his ability to get along with other children. These improvements were also reported verbally by his mother during the semi-structured interview and were highlighted by the researcher at the time of secondary observation.
- The reported changes in Matthew's ability to play with other children were highlighted by the researcher during the observation that took place at the second time point. Matthew was observed taking part in a turn taking game with another child, whereas during the observation at the initial stage of data

collection Matthew's play had been solitary. Additionally, his expressive language was less echolalic at the time of secondary observation.

4.1.4 Cross Case Analysis

Due to the small sample size and the heterogeneity of the sample it is impossible to make a meaningful cross case analysis of the data for all the children. The purpose of making a cross case analysis is to therefore focus on trends arising from the data where the children have either made expected patterns of development, or exceeded what would be expected, if compared to a 'typically' developing population of children.

4.1.4.1 Vineland Adaptive Behaviour Scales II

Three of the six children showed changes in a positive direction in their overall levels of adaptive functioning, as summarised by the 'Adaptive Behaviour Composite Score.' Jack's level changed from 'low' to 'moderately low', Christopher from 'moderately low' to 'average' and Rory from 'low' to 'moderately low.' On the other hand two of the six children namely Oscar and William, remained 'low' at both time points, and Matthew's level changed in a negative direction, from 'average' to 'moderately low' over the time period of the study.

Three of the six children made gains in their 'Expressive' language skills that were greater than expected over the time period of the study. Rory made a gain of 7 months, Christopher made a gain of 13 months and Oscar made a gain of 16 months in 'Expressive' language skills.

Two of the six children made age equivalent gains in their 'Receptive' language skills that were greater than what was expected over the study time period. Jack made a

gain of 36 months and Christopher made a gain of 15 months. Matthew's gain of 7 months is what would be expected if compared to a 'typically' developing child in a 7 month time period.

Three of the six children made gains in their 'Written' communication skills that were greater than expected over the study time period. Christopher made a gain of 21 months, Rory made a gain of 37 months and Oscar made a gain of 14 months. Jack's gain of 8 months is what would be expected if compared to a 'typically' developing child in an 8 month time period.

Three of the six children made gains in their 'Play and Leisure Time' that were greater than what was expected during the time period of the study. Jack made a gain of 22 months, Christopher made a gain of 9 months and Rory made a gain of 18 months. Matthew's development in this area of 7 months is similar to what would be expected of a 'typically' developing child during a 7 month time period.

Two of the six children made gains that were greater than expected over the time period of the study in 'Interpersonal Relationships.' Rory made a gain of 8 months and Matthew made a gain of 9 months in this area on the Vineland-II.

Two of the six children made gains in their 'Coping' skills that were greater than expected. Jack made a gain of 15 months and Oscar made a gain of 23 months in this area on the Vineland II.

4.1.4.2 Strengths and Difficulties Questionnaire

Three of the six children showed improvement in the assessment of their behaviour as measured by the SDQ. Both Jack and Christopher showed improvement in their

'Hyperactivity and Attention difficulties.' Christopher and Matthew showed improvement in their 'Ability to get along with other children'. However, Jack's score on the 'Behaviour Difficulties' scale was more negative at the time of secondary data collection.

4.1.4.3 Gilliam Autism Rating Scale-2

Of the six children in the study two children's classifications on the 'Autism Index' changed over the time period of the study. Jack had a score on the Autism Index that decreased and he therefore went from being classified as 'Possibly' having autism, to 'Unlikely' to have autism. Matthew was classified as 'Very Likely' to have autism at the time of initial data collection. His score on the Autism Index reduced at the time of secondary data collection and he was classified as 'Possibly' having autism.

4.1.4.4 British Ability Scales II – Early Years Core Scales

Cross case analysis of all the children's scores on the BAS-II is not possible as only four of the six children had both initial and secondary test scores. Where initial and secondary BAS-II data are available, all four children who were assessed at both time points showed progress on at least one of the subtests. Both William and Rory's General Conceptual Ability (GCA) standard scores changed in a positive direction. William's non-verbal cognitive ability went from being classified as being within the 'Very Low' range to being within the 'Below Average' range and Rory's changed from being within the 'Very Low' range to being within the 'Low' range over the time period of the study.

4.1.5 Summary of individual data

All the children in the study made some gains in their development, although it is clear that there is no overall pattern of development for the group. It appears that there are a number of factors, which have had an impact on individual patterns of development that were reported over the time period of the study. Further discussion of this will be presented in Chapter 5.

4.2 INTERVIEW DATA

Semi-structured interviews took place with the parents in the study in order to gather their views about their child's development over the time period of the study. Additionally, the researcher aimed to explore their views on the possible impact that their child's autism had had on the family, and their views on any specialist or non-specialist support and/or intervention that their children, or themselves had received. The purpose of this was to help inform the Local Authority, where the research took place, about appropriate support for this group of parents and their children in the period following a diagnosis of autism. Additionally, the researcher was interested in exploring whether any measured developmental change on the standardised measures matched parental perceptions about their child's development, as assessing this population of children can be problematic. This is due to the fact that often standardised measures and/or psychometric tests do not have standardised norms for this population of children, and therefore, the gathering of evidence from parents can act as a further source of evidence where changes are documented using such measurement tools. Additionally, it proved difficult to assess some of the children, due to the child's level of cooperation, and parental views, if accurate, could be used as an alternative source of information.

The following section will present the themes developed from the qualitative data through the process of thematic analysis. The qualitative data are based on five interviews with the parents of the children in the study which took place at the time of

secondary data collection. Oscar's mother, who was in the non-EarlyBird group of parents did not give consent to be interviewed. The qualitative analysis of the semi-structured interviews seeks to answer research question 2:

2. What are the views of parents participating and not participating in the Early Bird Programme on:

- *Perceived gains in their children's development*
- *The Impact of the EarlyBird Programme and/or other specialist or non-specialist provision?*
- *The Impact on the family of a diagnosis of autism?*
- *The factors that appear to be important in reducing the negative impact of a diagnosis of autism on the family?*
- *Challenges to access of the EarlyBird Programme?*

4.2.1 Analysis

All interviews were tape recorded and transcribed for analysis (Appendix 8). The interview data for each group of parents were then analysed separately using thematic analysis, a qualitative approach delineated specifically for use in psychology, as outlined by Braun and Clarke (2006). This technique was considered appropriate for two reasons. Firstly, the researcher aimed to identify common issues raised across the data sets, and secondly, thematic analysis gave the researcher the ability to use both data driven and theoretically informed coding in order to explore the participant's views.

It was decided to analyse the data using a practical thematic analysis framework as described by Aronson (1994). This involved a number of steps, which have been described below:

1. Reading and re-reading the whole transcripts. The researcher was encouraged to become familiar with the content of the interviews and begin to identify regular recurring experiences and feelings described by the parents through this process.
2. The emerging broad themes that were first identified under each interview question were 'mapped' on a computer system known as 'MindManager' (Appendix 9). This allowed the researcher to develop a clearer, visual picture of recurring broad themes that had developed under each question. Additionally, the links between different questions and their emerging themes was clearer when viewed in this way.
3. The researcher took these broad themes to supervision on a number of occasions and through the use of a narrative, explained the meaning of the themes and how these had emerged within the context of the interviews. These conversations gave meaning to themes and encouraged the researcher to submerge herself into the 'stories' that were initially being told through the process of 'to and fro' communication that took place when the interviews were being conducted. Additionally, this process encouraged the researcher to move back and forth between the initial analysis and the whole text in order to develop new understanding of the data.
4. The researcher then split all the initial themes away from their 'parent question' in order to gain a clearer view of the main themes that had emerged throughout the interview data, and not solely under the specific questions. This encouraged the researcher to use the themes to form a narrative, rather than seeing them as 'stand alone.'
5. A number of sub themes emerged that gave further meaning to the main themes. These were then input into a table with quotations from the text in order to give meaning to the data.

The method of analysis ensures that all themes can be systematically traced back to the raw data and, therefore, offers a level of reliability and validity for the analysis (Braun & Clarke, 2006). In order to further this reliability a sample of 50% of the data were given to a colleague who followed the same process of analysis to check the reliability of the themes that emerged. The themes for 'Both groups of parents,' 'the EarlyBird group of parents' and the 'non-EarlyBird group of parents' are presented with example quotations from the interview transcripts.

4.2.2 Results

The results of the thematic analysis of the interview data will be presented under three subheadings. These include:

- Both Groups of Parents
- EarlyBird Group of Parents
- Non-EarlyBird Group of Parents

The purpose of presenting the data in this way is that a number of the interview questions were presented to both groups of parents, and some were not. The data gathered from all the parents interviewed and the resulting themes that emerged will be presented under the heading 'both groups of parents.' On the other hand, data that were specific to each group of parents has been separated and presented under the headings 'EarlyBird group of parents' and 'Non-EarlyBird group of parents.'

Under each main theme is a diagram in order to show the theme and subthemes, as well as table specifying which children's parents spoke about the theme being discussed. In addition, in order to illustrate the themes some example quotations have been included under each theme and their sub-themes.

4.2.2.1 Both Groups of Parents

Three themes and the linked subordinate themes emerged through the process of thematic analysis of interview data from both groups of parents. The following themes relate to research question 4, specifically:

- *What are the views of parents participating and not participating in the EarlyBird Programme on:*
 - *The impact on the family of a diagnosis of autism?*

The themes that emerged were: 'Grief Reaction', 'Perception of Blame from Others' and 'Exclusion and Isolation.' These themes are presented below with example quotations from the transcripts. The name of the child whose parents made the comment has been put in brackets as well as whether the parent making the comment was in the EarlyBird group of parents (EB) or in the non-EarlyBird group of parents (Non-EB).

4.2.2.1.1 Theme 1: Grief Reaction

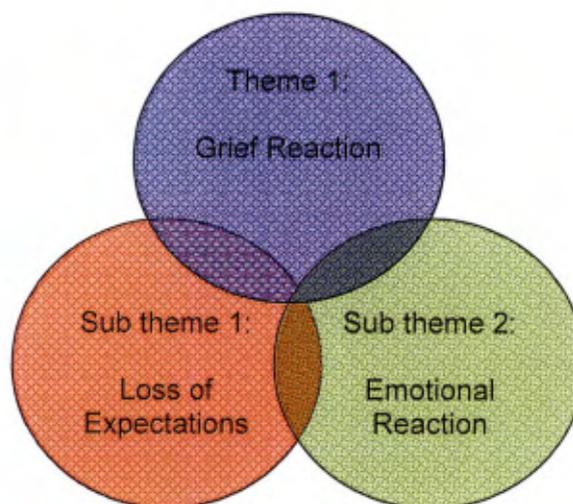


Figure 2: Theme 1

Child's Parents	Jack (EB), Christopher (EB), Rory (EB), William (Non-EB) & Matthew (Non-EB)
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Two sub-themes related to the theme of 'grief reaction.' These included the parents' initial shock at the 'loss of expectations' that they had for their child when a diagnosis of autism was given, as well as the 'emotional reaction' that parents experience when this occurs.

4.2.2.1.1.1 Sub theme 1: Loss of expectations

Three of the five parents interviewed spoke about how a diagnosis of autism when their child was over the age of one year was extremely difficult to cope with and often it felt like one was losing a child. Jack's mother spoke about how 'you mourn the loss' of the child that you now do not have as when your child is born you believe that he is 'perfect' and imagine a certain type of life for him.

"If you have a child you want it to be perfect, and then you get a diagnosis of autism and it kind of blows you away. You sort of mourn the child that you now don't have." (Jack's mum - EB)

All five of the parents interviewed stated that one of the main difficulties with autism is that it is a disability where the child does not 'look' disabled (a theme that re-emerges later on) and therefore, only when he reaches a certain age do you as a parent realise that there is something wrong.

"He looked fine. He was so much like his brother. It was fine. You don't really think about it. It was only later when he was coming on two. I think we knew deep down though." (Matthew's mum – Non-EB).

4.2.2.1.1.2 Sub theme 2: Emotional Reaction

The parents' emotional reaction to the diagnosis of autism was similar in all the participants interviewed. There was a clear pattern where four of the five parents interviewed appeared to firstly go through a period of depression and stress, usually due to the long period of diagnosis,

"We are quite a happy family; the first year was harder, much more stressful, going through the diagnosis. It took ages." (Matthew's mum – Non-EB).

"The more you start seeing it [autism] as a problem you get depressed and you get into the mindset that it is a problem and you always see the negative side of it. It weakens you and you can't deal with it properly." (Jack's mum - EB)

"I always look on the dark side of life, I suffer from depression." (William's mum – Non-EB)

Secondly, four parents reported that they went through a period of denial, which links with the sub theme of 'loss of expectations' as the shock of being told that your child has a life-long disability causes the parents to deny that this can be true.

"You go through a whole denial thing and have fights with the family. Then the diagnosis comes in and you accept it. Initially you are so shocked and everything is bad. Everything is negative. You see him [the child] as not normal. You separate him from the normal." (Jack's mum - EB)

"We were concerned early on but it took a while to decide to go and make the step and see the doctor." (Matthew's mum – Non-EB)

"It has been very hard to accept it. I think his dad hasn't yet. He still treats him like a normal child. He is very firm but not flexible." (Christopher's Mum - EB)

"I was concerned and I thought that we needed to take him to see someone. She said that he was fine and there was actually nothing that they could do about it [activity levels]." (Christopher's mum - EB)

"He is little, I thought maybe they had it wrong." (Rory's mum - EB)

Finally, it appeared from the interviews of four of the five parents that they may accept that their child has autism and learn to see them differently and accept that there will be difficulties but that these can be dealt with. Acceptance leads to parents seeking support, which is one of the other themes that emerged from the data.

"Very hard acceptance, I did eventually accept." (Christopher's mum - EB).

“...it is all labels and it is about how you are going to accept those and get the help that you need.” (Rory’s mum - EB)

“You have to learn to see them in a different light and accept them for who they are. It is only a problem if you make it a problem.” (Jack’s mum - EB)

“His behaviour is sometimes difficult but I accept it as part of his difficulties and accept that certain things are part of the parcel; I don’t see him as anything negative.” (Matthew’s mum – Non-EB)

4.2.2.1.2 Theme 2: Perception of blame from others

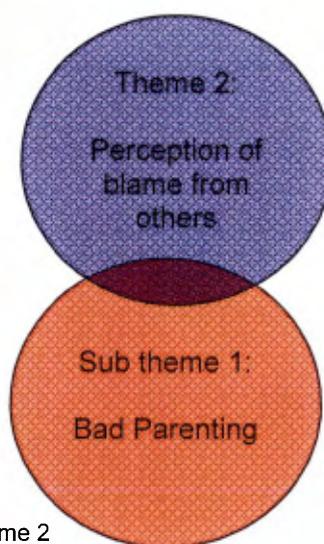


Figure 3: Theme 2

Participants Parents	Jack (EB), Christopher (EB), Rory (EB), William (Non-EB)
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The second theme that emerged from the data was other peoples’ perceptions of the participants as parents, and of their children. This theme was a very powerful one, and it appeared from the interviews that four of the five parents interviewed found it very difficult to deal with the way that they perceived other people’s thoughts of them as parents when they were out in the community with their child with autism.

“The parents think that we are to blame, he has no discipline.” (Christopher’s mum - EB)

This was especially true when their children had a difficult day and displayed challenging behaviour, which they perceived other parents as not understanding and therefore seeing them as bad parents. One sub-theme was related to this theme, namely, 'bad parenting.'

4.2.2.1.2.1 Sub theme 1: Bad parenting

Under the theme of 'perception of blame from others' fell one further sub-themes. Four of the five parents who were interviewed expressed that the difficulty with having a child with autism is that the child does not look like they have a disability, and therefore, people outside the family view the parents as bad parents who do not discipline their children.

"He looks just like his brother; things are fine and then suddenly all hell breaks loose 'cause something happens. I usually have no idea what. Everyone looks at you. You can see them thinking, 'bad mother.' (Rory's mum - EB).

"He went through a phase that he would not wear a jacket, it would be outside and he would refuse to wear a jacket and there would be people walking past and looking. I would even put it on the other way, but he'd still get out of it. It got to the stage that if it looked like it was going to rain we wouldn't go out, we couldn't, I don't have a car, I can't go to certain places, I can't queue up, he creates hell." (William's mum – Non-EB).

Both Christopher and William's parents spoke about how they felt they had been viewed by the professionals that they went to for help as 'bad parents,' which made them angry and contributed to the feelings described under the first theme, 'grief reaction'.

"We then went down to the health visitor, I wasn't particularly impressed, she was from the old school and blamed us. Said he was pampered too much." (Christopher's mum - EB).

"I took him to the speech and language drop in and was basically told that I was not talking or playing enough with him." (William's mum – Non-EB).

4.2.2.1.3 Theme 3: Exclusion and Isolation

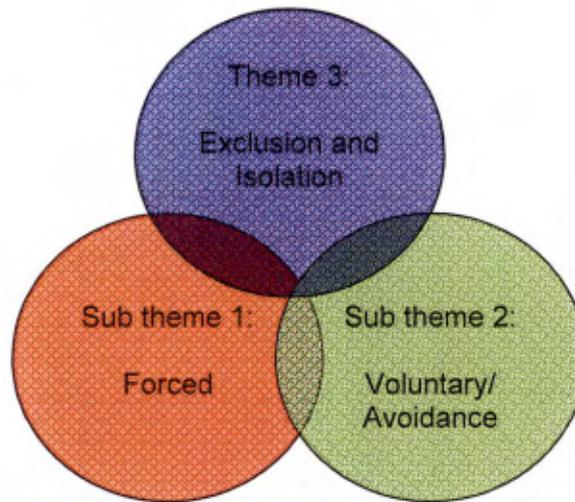


Figure 4: Theme 3

Child's Parents	Christopher (EB), Rory (EB), William (Non-EB), Matthew (Non-EB)
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Two subthemes emerged under the theme 'exclusion and isolation,' namely, 'forced' and 'voluntary/avoidance.' The sub themes were closely related to each other as it appeared that forced exclusion and isolation eventually led to parents purposefully electing not to join in community activities, as well as restricting activities outside the home due to the difficulties arising from such outings.

4.2.2.1.3.1 Sub theme 1: Forced

Four of the five parents interviewed spoke about how other families had excluded them due to the behaviours that their children exhibited when out in the community. Initially their exclusion was forced, as people stopped inviting them out.

"It has definitely impacted on the possibility of going out and joining in with friends of his age. We don't get invited out. It impacts on all of us as we are excluded."
(Matthew's mum – Non-EB).

"We don't get invited out. Halloween for example, they all went out and he wanted to go but he had been excluded" (Christopher's mum - EB).

"Other children are scared of him. They don't want him at parties and stuff" (Christopher's mum - EB).

4.2.2.1.3.2 Sub theme 2: Voluntary/Avoidance

Forced exclusion appeared to become voluntary after some time as parents and their families needed to plan their day around the child with autism. Two of the five parents interviewed reported that often it was easier to not go out at all.

"We have to plan our day, our life around [child's name],the autism is family life really" (William's mum – Non-EB).

"Sometimes it is easier to just not go out." (Rory's mum - EB).

4.2.2.1.4 Theme 4: Impact on Siblings



Figure 5: Theme 4

Child's Parents	Jack (EB), Christopher (EB), Rory (EB), William (Non-EB), Matthew(Non-EB)
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All five parents interviewed spoke about the effects that their child's autism had had on the child's siblings. Jack's mother did not speak about negative effects, but rather that his autism had impacted them in a positive way and made them more tolerant and understanding. All four other parents spoke about how initially the effects were

negative, and Matthew's mum spoke about how his brother was coping well now due to the improvements in Matthew's play skills. On the other hand, William, Rory and Christopher's parents did not talk about any positive impacts of their child's autism on the child's siblings.

"Socially, he is much more sociable, which has mainly been due to his older brother more than anything. He's the absolute best therapist. [child's name] is obviously at the right stage and then he's got [brother] desperately wanting to play so that's really helped, particularly over the summer holidays, they were brilliant." (Matthew's mother).

I was more concerned about [brother] 6 months ago. He has become very sensible and responsible, responsible for [child's name].(Matthew's mother).

When this viciousness and not listening to what I was saying to him. He was biting his sister all the time. The aggression was always directed towards her. (Christopher's mother).

"Little one misses out on so much. He is always on the sidelines; everything revolves around [child's name]." (William's mother).

4.2.2.2 EarlyBird Group of Parents

Three themes and the linked sub themes emerged through the process of thematic analysis of interview data from the EarlyBird group of parents. The themes that emerged were: 'Parental Support', 'Professional Expertise' and 'Inclusion.' These themes are presented below with example quotations from the transcripts. The name of the child whose parents made the comment has been put in brackets after each example quotation. The following themes relate to research question 4, specifically:

- *What are the views of parents participating and not participating in the EarlyBird Programme on:*
 - *The impact of the EarlyBird Programme and/or other specialist or non-specialist provision?*

4.2.2.1 Theme 1: Parental Support

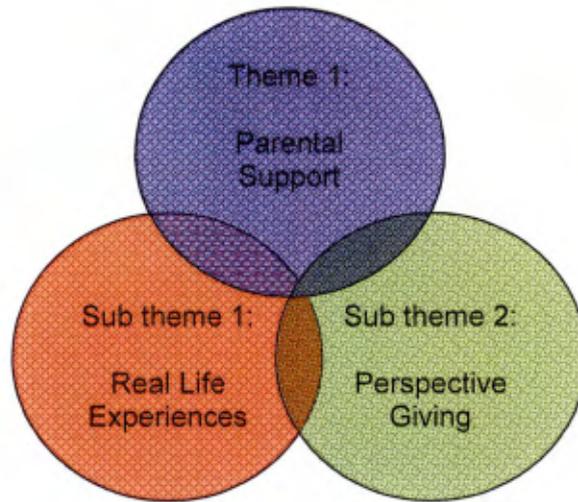


Figure 6: Theme 1

<i>Child's Parents</i>	<i>Jack, Christopher, Rory,</i>
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Under the theme 'parental support' fell two subthemes. These included 'real-life experiences' and 'perspective giving.'

All three of the EarlyBird group of parents spoke about how they felt that the support they had gained from other parents, who also had children with autism, was invaluable and often more valuable than the knowledge they gained through books and other formal resources.

4.2.2.1.1 Sub-theme 1: Real-life experiences

The three parents in the EarlyBird group reported that having the opportunity to meet with other parents during the EarlyBird Programme was valuable to them as there other parents there who could talk about their own experiences of dealing with their child with autism.

“Some of these parents have got children who have gone through this and they can help. You know, real life experience.” (Jack’s mum)

“It is great and brilliant to talk to other parents.” (Christopher’s mum)

4.2.2.1.2 Sub-theme 1: Perspective giving

Both Jack and Rory’s parents spoke about gaining a sense of perspective about their child (for example, ‘having less issues’) and often realising that they were not alone in the difficulties that they were dealing with.

“It is amazing how many people cry and they always think they are dealing with it alone. It makes it easier when you know that you are not alone.” (Jack’s mum)

“There were a lot of things that I was hearing about that other people were dealing with, which I was not and it helped to give me back my perspective. Um, yeah when you are having less issues it does give you a sense of perspective back.” (Rory’s mum)

4.2.2.2.1 Theme 2: Professional expertise

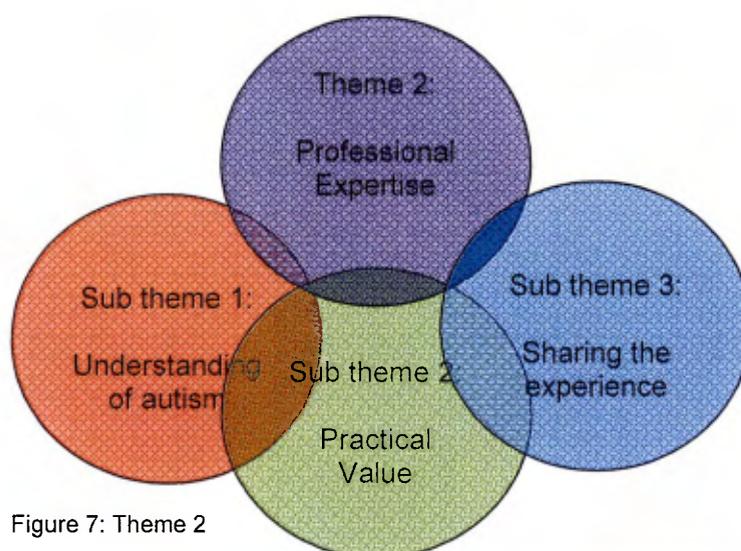


Figure 7: Theme 2

Child’s Parents	Jack, Christopher, Rory,
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Three sub themes emerged under the theme 'professional expertise.' These included 'understanding of autism,' 'practical value' and 'sharing the experience.' All three parents who took part in the EarlyBird Programme expressed that they were extremely satisfied with what they had learnt from the professionals running the course.

"Whether we would have found this out and learned through media alone, I doubt it. It has been through the contact with other people, the professionals, the reports and EarlyBird." (Jack's mum)

"We just learned lots about how he might view himself as he gets older as he is very clever and verbal. What we have learned for an ongoing future. We took out their expertise, their care." (Christopher's mum)

4.2.2.2.1.1 Sub- theme 1: Understanding of autism

Two of the three parents in the EarlyBird group reported that their own understanding of autism, which had emerged because of the programme, was unique, and that they felt they could not have gained this from other sources.

"...the understanding of what autism means. It was just a scary word before." (Christopher's mum).

"learning to follow routines and help him make sense of the scary world. We had no idea about the sensory stuff and this really applies to him." (Rory's Mum).

4.2.2.2.1.2 Sub- theme 2: Practical Value

The strategies and practical resources that were offered emerged as a strong theme throughout the interviews. All three parents interviewed in the EarlyBird group reported that they felt more skilled to put processes into place within the home environment that would help their child. They expressed that they felt they would not have gained this knowledge through other means.

“The most useful was the strategies, the practical stuff. Sand timers and routine and things like that.” (Jack’s mum)

“I think the strategies that I got from EarlyBird were unique.” (Rory’s mum)

“The ideas and the systems we could perhaps put into action and try a lot of. At first we thought that’s not [child], we shouldn’t really be here, but towards the middle and end we thought that they were pertaining to him, especially the sensory thing. He knows how to follow a routine now.” (Christopher’s mum).

I learned a lot of things about how [child] thinks and I learnt a lot of strategies. I bought a laminator; I was laminating cards to help him with routines and stuff. I found it really helpful, the videos and stuff. Yeah, I found it really helpful.” (Jack’s mum).

4.2.2.1.3 Sub Theme 3: Sharing the experience

Two of the three parents interviewed reported in the interviews that having their partner present during the EarlyBird Programme had made them feel more supported. They reported that their feelings of being the sole person in the family responsible for supporting their child’s needs on a daily basis had been reduced. Rory’s mother reported that this support had made her feel less stressed.

“Having [partner’s name] there was great. They [EB Programme] encourages this and it makes sense. I felt so much better that we could do it together. We both became responsible for sharing the information and making sure things were working for [child’s name] at home.” (Christopher’s mother)

“As a mum you feel like you need to do it all. [partner’s name] is always at work and when he comes home I feel like I must have it all in control. It was nice that he was part of it. I felt less stressed about [child’s name] behaviour because [partner’s name] was also having to understand it.” (Rory’s mother).

4.2.2.2 Theme 3: Inclusion

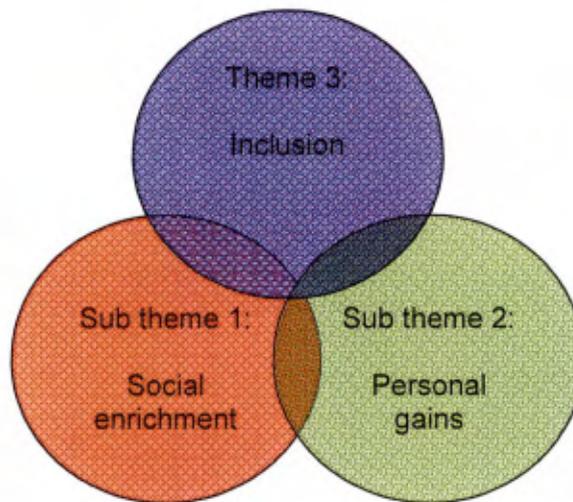


Figure 8: Theme 3

<i>Child's Parents</i>	<i>Jack, Christopher, Rory,</i>
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One of the themes that emerged for this group of parents was 'inclusion.' This theme emerged due to parents being questioned about what they felt has contributed towards the progress that they had seen in their children over the past six months. Two subthemes, namely 'social enrichment' and 'personal gains' emerged under this theme.

4.2.2.3.1 Sub theme 1: Social Enrichment

All three parents in the EarlyBird group expressed that they felt their children had made gains in communication and social interaction due to their interactions with children who do not have autism. This included their siblings as well as children at school. All three children whose parents were in the EarlyBird group attended mainstream provision. Parents also expressed that the understanding of other professionals (teachers) had impacted on their children's progress due to their children being encouraged to interact with other children, as well as routines and structure being put into place.

"Since he has been at school he has definitely learnt to play." (Jack's mum)

“He seems to have noticed that his brother gets what he wants by communicating appropriately. He has started to do this too now.” (Rory’s mum)

“A lot [of his progress] is due to the input that he is being given in the school environment.” (Jack’s mum)

“If he is progressing at the rate that he is now, hopefully he will continue in mainstream. He is learning to accept discipline.” (Christopher’s mum).

4.2.2.3.2 Sub theme 2: Personal Gains

The sub theme ‘personal gains’ included the parents talking about issues such as, ‘awareness’ and ‘tolerance.’ Two of the three parents in the EarlyBird group spoke about the positive impact that having a child with autism had had on their family, as well as other people around the child.

They felt that having their children included in a mainstream environment was good for their peers as it encouraged understanding and tolerance. One parent spoke about how schools were so different now to what she had experienced as a child, where there were no children with special educational needs in her class.

“I always thought that naughty children came from bad homes, split homes, homes where the adult members had problems. It really made me sit back and think, wow, there are so many children out there who are not just naughty.” (Christopher’s mum)

“It makes you more tolerant and helps normal kids be more tolerant.” (Jack’s mum)

4.2.2.3 Non-EarlyBird Group of parents

Three themes and the linked sub themes emerged through the process of thematic analysis of interview data from the non-EarlyBird group of parents. As only two out of the three parents in this group gave consent to be interviewed all themes that emerged were as a result of them being present in both William and Matthew's parent's interview transcript data. The themes that emerged were: 'Challenges to Access, 'Provision and 'Informal Parental Support.' These themes are presented below with example quotations from the transcripts. The name of the child whose parent made the comment has been put in brackets after each example quotation. The following themes relate to research question 4, specifically:

- *What are the views of parents participating and not participating in the EarlyBird Programme on:*
 - *The impact of specialist or non-specialist provision?*
 - *Challenges to access of the EarlyBird Programme*

4.2.2.3.1 Theme 1: Challenges to access

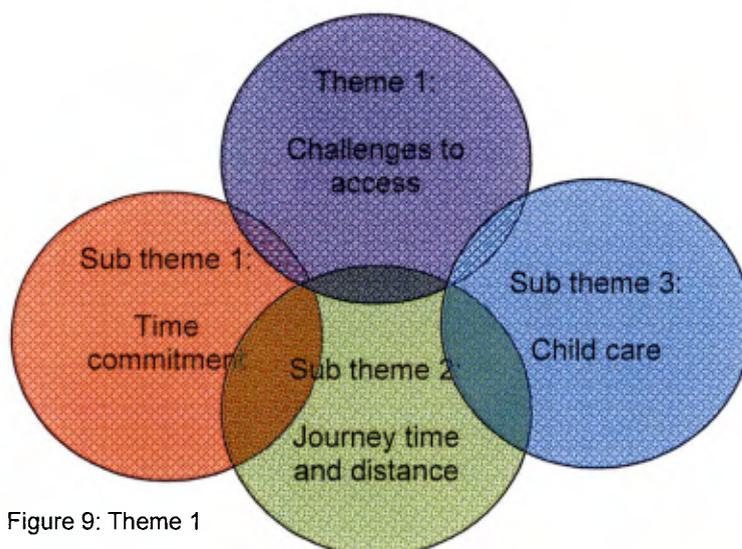


Figure 9: Theme 1

Child's Parents	William, Matthew
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The first theme that emerged was 'challenges to access,' which was an important theme, as it provided the researcher with the rationale of the non-EarlyBird group of parent's unwillingness to take part in the EarlyBird Programme. Additionally, this theme highlighted the difficulties that parents face on a daily basis with their children with autism and the types of support that could be provided as an alternative to structured, timed intervention programmes.

4.2.2.3.1.1 Sub Theme 1: Time Commitment

The EarlyBird programme is run for a period of 13-weeks every Friday morning. The two parents who were interviewed in the non-EarlyBird group both spoke about how they felt that they could not commit to this.

*"It was also quite a commitment, it was every Friday, and it was quite a journey."
(Matthew's mum)*

*"..having it in the morning. Cause most kids are at nursery in the morning, so if they took into account that we have a three hour window in the morning we could do it while they are at school."
(William's mum)*

4.2.2.3.1.2 Sub Theme 2: Journey Time and Distance

All participants who took part in the study, including those that did take part in the EarlyBird programme lived, on average, 16 miles from the location where the programme took place. The parents in the non-EarlyBird group spoke about how the journey was long and William's mother did not have access to a car of her own.

*"we couldn't, I don't have a car."
(William's mum)*

*"It was also quite a commitment, it was every Friday, and it was quite a journey."
(Matthew's mum)*

4.2.2.3.1.3 Sub Theme 3: Child Care

The programme was run weekly for a period of 13 weeks, additionally, 5 of the 6 participants had other children who would either require child care, or fetching from school/playgroup. Additionally, Matthew's mother highlighted that he found it difficult to deal with change and new environment, and therefore, leaving him in a strange crèche would not have been viable.

"I don't have anyone around here to look after [younger brother], so I couldn't go for an afternoon. I don't have any child care, which was a major factor." (William's mum)

"I would have to have taken him as I have no family here to look after him, I know that there are crèches but I was concerned about how he would cope with a new environment." (Matthew's mum)

4.2.2.3.2 Theme 2: Provision



Figure 10: Theme 2

Child's Parents	William, Matthew
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The third theme that emerged for this group of parents was 'Provision.' Matthew was attending a mainstream pre-school and William had been attending a special school for children with autism and learning difficulties for three months at the time of the interview. Both parents spoke about how the school that their child was attending had impacted on their development over the past six months.

"[he] has just started to be able to copy other children's behaviours, he has been copying W [his brother] but also in the school playground." (Matthew's mum)

"I am sure that [pre-school] has also been amazing, he gets forced into being social." (Matthew's mum)

"He started [special school] in September and that was when I think there was the biggest change. When he was at [old school] he was just left to do all his autistic things on his own, but at [special school] they are more structured they know what they are doing which has made him a lot happier in himself." (William's mum).

4.2.2.3.3 Theme 3: Informal Parental Support



Figure 11: Theme 3

Child's Parents	William, Matthew
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The final theme that emerged was 'informal parental support' as both parents in the non-EarlyBird group spoke about how a 'live' forum in local areas would provide the support that was needed after a diagnosis of autism. Both parents were aware that they had needed support from external sources during the period immediately following a diagnosis, although due to the issues that were discussed above, under 'challenges to access,' had not received adequate support.

"I know I needed support but the most support I have had is off the forum, talking to parents, if I have a problem I will post something up and get 7 or 8 different points of view. I can then try one thing and another if it doesn't work. They have been the most support." (William's mother).

Some of these parents have got children who have gone through this and they can help. You know, real life experience, rather than some person writing a book and you

paying £9.99 and can read it, oh woopdee. It would be great to talk to them more. Maybe a local support group or something.” (William’s mother)

“I suppose if we could have had some sort of group where it would have just been nice to go and talk or to meet some other parents I think, with some children there, like a mother and toddler group. Maybe have a professional leading that. I know the SALT group is a bit like that. That might have been a bit easier. Also, I think getting to hear other people’s experiences would be very useful.” (Matthew’s mother).

4.2.3 Summary of interview data

The qualitative themes that emerged from the interview data are supported by the current literature on autism and its impact on the family. The interview data that was central to understanding the families’ perceptions of the EarlyBird Programme, as well as other forms of support, will be discussed further in Chapter 5. Additionally, a discussion of themes that emerged which have not been explored in the current literature, and have further implications for professional practice, will also take place.

CHAPTER 5

DISCUSSION

The current research utilised a mixed methods approach to answer the research questions presented in Chapter 2. The use of both quantitative and qualitative data has provided the researcher with a deeper understanding of the individual patterns of development of the children, the impacts of having a child with autism on the family context as a whole and the perceived impacts of the EarlyBird Programme and other specialist support and provision on the child and the family.

Conclusions are based on an overall picture of the experience of these parents and the patterns of development of their children derived from an aggregation of qualitative and quantitative data.

The following chapter presents a discussion of the main results of the study, outlined in Chapter 4, highlighting the implications that these results will have for professionals working with this population of children and their families.

5.1 FINDINGS

The findings that have emerged as a result of the data that was gathered are presented below under the two research questions and sub questions that were presented at the end of Chapter 2.

5.1.1 Research Question 1:

Can we measure the individual patterns of development, and the factors that appear to be important in encouraging any measured development, of

a group of pre-school children with autism in aspects of their cognitive functioning, communication and language skills, social interaction and adaptive behaviour?

Five of the six children who took part in the study showed some gains in their development that were greater than expected in the study time period. However, as would be expected, different individual patterns emerge and there is no clear overall pattern. Due to the heterogeneity of the group these improvements cannot be specifically attributed to any one factor. As can be seen from the individual participant profiles and case study data a number of factors; for example school placement, reduction in hyperactivity, increased attention span and having siblings, could have contributed to the changes in development that were reported for the children.

Three of the six children, Jack, Christopher and Rory, showed improvement in a positive direction in their overall levels of adaptive functioning, as measured by the Vineland-II. Two of the three children, namely Oscar and William, showed no improvement in their overall levels of adaptive functioning and Matthew's overall level of adaptive functioning changed in a negative direction. It would be expected that those children who made greater gains in some of the subdomains on the Vineland-II than expected would also show improvement in their adaptive functioning levels. Additionally, where skills such as 'written communication' had developed at a much quicker rate than expected, for example, Rory (37 months) and Christopher (21 months); this would also have affected changes in their overall levels of adaptive functioning. Matthew's development was reported as positive by his mother, and improvements were also observed by the researcher, yet his overall adaptive behaviour level, as measured by the Vineland-II changed in a negative direction. It could be suggested that there are issues with measurement reliability, or that Matthew's mother perhaps scored him more negatively at the time of initial data

collection and was then more realistic at the time of secondary data collection, which could have impacted on his reported gains on the Vineland-II.

Four of the six children made gains in their communication skills that were greater than expected over the time period of the study. Jack and Christopher showed greater gains in their receptive language skills and Rory, Christopher and Oscar in their expressive language skills. Both Jack (36 months) and Christopher's (15 months) gains in their receptive language scores are unusual. They were both observed to be responding to adult instruction better during the secondary observation, and it was also noted that their levels of hyperactivity had reduced and attention span had increased. These changes were also noted on the SDQ. It is unclear whether the reported change on the Vineland-II reflects actual gains in receptive language, or whether improved attention span and reduction in hyperactivity has led to the perception that they have a better understanding of language than they did previously.

On the other hand, it was interesting that Matthew was the only child in the group that did not make greater gains in this area than expected, yet he was receiving Speech and Language Therapy at the time of the study. However, when focussing on observational data, Matthew appeared to be the calmest of the children, and his SDQ score for 'Hyperactivity and Attentional Difficulties' was also reported to be 'close to average' at both time points. Perhaps without the presence of such behaviour it was clearer to his mother when scoring the Vineland-II whether he had in fact made gains in this area as his physical behaviour and attention span were not extraneous variables that may have affected the scoring.

Three of the six children, namely Jack, Christopher and Rory, showed greater gains than expected in play and leisure time, as measured by the Vineland-II, in the study time period. Observational data of these children did indicate that their ability to play with other children had improved, although this was also the case for Matthew who did

not make greater gains than expected in this area on the Vineland-II. However, Matthew's development in this area was in line with what would be expected when compared to a 'typically' developing child, as he made 7 months progress in a 7 month time period.

Two children, Rory and Matthew, made greater gains in interpersonal relationships than expected in the study time period. These gains were also recorded in the observational notes for both these children, and reported by the children's parents. Although Matthew made gains in this area he did not make greater gains than expected in play and leisure time, as already discussed. Perhaps his overall play and use of leisure time was still quite rigid, as observed during the initial observation period. Additionally, Matthew's special interest with the solar system was reported by his mother during the interview. Although his relationships with other children had improved perhaps he was still reluctant to join in with games which did not involve his own interests.

Two of the six children, Jack and Oscar, made gains greater than expected in their coping skills as measured by the Vineland II. Oscar's mother reported that he was able to go to school without her present for the first time. This would have impacted on his score. Unfortunately observational data at the second time point is not available for Oscar. It would have been useful to have had this data to make comparisons over the two observations.

Two of the six children in the study's GARS-2 scores changed in the study time period. Jack's Autism Index Score decreased and he was therefore classified as 'Unlikely' to have autism. Jack is the only child in the sample with an additional diagnosis, Fragile X Syndrome. He also has the lowest cognitive ability score, which raises the question of whether Jack has autism, or whether the combination of his 'Very Low' cognitive ability and Fragile X Syndrome have impacted on his overall development. Matthew's GARS-

2 score also decreased and he was classified as 'Possibly' having autism. Although this is the case, Matthew is one of the children in the sample who presented as having a high severity of autism during both observations. This therefore raises the question of whether the GARS-2 is in fact a reliable measure of autism severity.

Where initial and secondary BAS-II data are available, all four children who were assessed at both time points showed progress on at least one of the subtests. These changes appear to be related to the children's increased ability to remain seated in a formal testing environment, and may be related to development in vocabulary skills between the two time points. This begs the question of whether these scores are in fact 'true' scores, or whether the child's mood on the day as well as maturation has impacted on their scores.

The concept of 'resolution of diagnosis' (Pianta & Marvin, 1993) was discussed in the literature review. Pianta & Marvin (1993) reported that parental acceptance of their child's diagnosis leads to improved parent-child interaction as well as attachment status. Although not all the literature suggests that having a child with a disability necessarily causes distress, four out of the six parents in this study indicated in interview that they found the diagnosis distressing. It could be hypothesised that if parental support through the EarlyBird Programme led to parents resolving their grief and other distressing emotions that emerged as a result of their child's diagnosis sooner, they would find it easier to be attuned and responsive to their child. If indeed this was the case, and the parental interactions improved for the EarlyBird group of parents, positive interactions between parent and child could also have had an impact on the child's developmental course. The three children whose parents took part in the EarlyBird Programme showed improvement in a positive direction in their overall levels of adaptive functioning, as measured by the Vineland-II, whereas the three children's parents who did not take part in the EarlyBird Programme did not.

All children in the study had had a change of educational provision between the two data collection time points. This was due to the time line of the study running through September, which is the start of the new academic year in the UK. Changes from one pre-school to another pre-school took place or from pre-school to reception year, according to the age of the child. Differences in structure, environment, teaching style and staff support are factors that could have, therefore, impacted on the scores that were achieved. These changes could have also impacted on the children's Vineland-II scores, especially in the area of 'coping skills' and 'independence.' Oscar's mother reported on the Vineland-II form that Oscar had managed to go to school without her staying with him, which he had not managed to do before. This 'normal' developmental step into formal education, and the natural developmental maturation that takes place during the pre-school years, should therefore not be forgotten or discounted when interpreting the results of the study.

Two of the children in the study, namely Jack and Matthew have older siblings, and three of the children, namely Christopher, Rory and William have younger siblings. One child, Oscar has no siblings. All children in the study, apart from William, made some gains on the Vineland-II that were greater than expected in the study time period. Four of the five children with siblings showed improvement in either their 'play and leisure time' and/or their 'interpersonal relationships' that was greater than expected in the study time period. Although it has been suggested (Knott, Lewis & Williams, 1997) that the presence of siblings in the child's life may encourage the development of social interaction, increased interest in others and language development, conclusions cannot be drawn from this sample.

Both Jack and Matthew were receiving additional specialist support throughout the duration of the study. Jack received support from an occupational therapist and a physiotherapist and his parents also took part in the EarlyBird Programme. His GARS-2 scores changed in the study time period and at the time of secondary data collection

his 'Autism Index' score indicated that he was the only child in the study who was 'Unlikely' to receive a diagnosis of autism at the time. It could be suggested that Jack, who appeared to make the most gains of all the children in his development over the time period of the study as measured by the Vineland-II, was receiving the most support. Additionally, he appeared to have the lowest severity of autism score, as measured by the GARS-2, of all the children in the study. Perhaps the combination of high levels of child and family support, and low levels of autism severity positively impacted on his development in the study time period. On the other hand, Matthew's additional Speech and Language Therapy support did not appear to have an impact on his Vineland-II scores, although as with Jack, his GARS-2 Autism Index score also changed and he went from being 'Very Likely' to receive a diagnosis of autism at the time of initial data collection, to 'Possibly' receiving a diagnosis at the time of secondary data collection.

The actual gains that were made by the children during the study time period may be less than what has been reported. It is accepted that perceived gains in the children's development may be due to a variety of factors, these include: social desirability of reporting positive changes following taking part in programmes/interventions, enhanced observation skills of parents, and the difficulty that parents may have disentangling maturation from treatment gains, as documented by Girolametto, Tannock and Siegel (1993). It appeared from the interview data that two of the three parents in the EarlyBird group were less stressed during the time that the interviews took place, although this change was not necessarily due to participation on the programme, but rather the increased support from their partners as encouraged by the EarlyBird Programme. This may have led to the mothers feeling more able to cope and consequently they may have viewed their child's difficulties from a different perspective. If parental perception of the child becomes more positive due to positive changes taking place, such as a possible reduction in stress, parents may perceive their child as being more capable in some areas than they actually are. In this study parents

participating in the EarlyBird Programme were likely to be well motivated because of their commitment to the programme. Participating in the programme may itself enhance their level of observation skills of their children's behaviour.

Although the measures used were standardised and have reported reliability and validity information (see Chapter 3), it must be highlighted that these scores rely on parental report. The changes that were reported verbally and through the standardised measures may be due to developmental changes in the child, or may be related to changes in the parent, such as their skill development and possible reduction in stress or a number of other unreported factors.

5.1.2 Research Question 2:

What are the views of the parents participating and not participating in the EarlyBird Programme on:

5.1.2.1 Perceived gains in their children's development?

Both groups of parents reported gains mainly in the areas of communication, independence and play on the Vineland-II. Parental verbal reports in interview of perceived gains in their children's development appeared generally to match the reported gains that were measured on the Vineland-II. Considering the reported difficulties in assessing children with autism (Charman & Howlin, 2003) and the difficulties that were experienced when undertaking this study regarding the utilisation of standardised assessments to measure cognitive abilities, it is encouraging to find consistency in parental reports documenting their child's abilities. This finding was also reported by Charman et al. (2004), where it was found that parental reports on the Vineland-II showed encouraging developmental progress in the children in their study, which was consistent with parental verbal reports and other standardised measures.

5.1.2.2 The impact of the EarlyBird Programme and/or other specialist or non-specialist provision?

In the literature review it was highlighted that some early intensive programmes can place additional stress on the families due to the intense input and commitment required to take part (Koegel, 2000). It was also suggested that there can be a negative effect upon the dynamics of the family, which could affect parental relationships as well as siblings. From the parental comments in interviews in this study, this does not appear to have been the case for the parents who took part in the EarlyBird Programme. One reason for this may have been due to practical arrangements, including the fact that economically there were no great demands on the families, additionally, there was no need for siblings to have their routines (e.g. school attendance) disrupted. It does appear from the parental sample in this study that the families who attended the EarlyBird Programme described themselves as having 'high' socio-economic status.' Perhaps the economic costs of providing transport and child care, which are not provided by the programme, are too burdensome for parents who are opting out of taking part in such programmes. This could mean that parents with greater financial burdens are missing out on the opportunity to receive support that is provided through programmes such as the EarlyBird Programme.

Both parents are encouraged to attend the programme and to work together. The manual states, "*whenever possible, fathers are encouraged to attend the sessions with their partners. In this way parents can learn together and support each other during (and after) the programme*" (Shields, 2000, p.24). The parents in the EarlyBird group reported that they had attended the programme with their partner/husband. Reducing the burden on the mother, as the sole person responsible for attending and disseminating information to the rest of the family, could reduce maternal stress. This was a factor that was referred to during the interviews by two of the three mothers in the EarlyBird group of parents. Additionally, one mother specifically reported that this had made her feel less stressed. It could therefore be suggested that encouraging the

presence of both parents/carers in support groups/programmes may result in reduced levels of stress for the mother. Once again, having a third group in this study would have been interesting where such contact and support could have been encouraged to explore whether maternal support from the child's father/male carer without a formal programme results in a reported reduction in stress levels. Additionally, the inclusion of an objective parental stress measure in this study, such as the Parenting Stress Index (Abidin, 1983) would have been more beneficial than interviews alone. In the context of this study this measure was not used due to time limitations and the researcher not wanting to overload the parents with questionnaires to complete.

Both groups of parents reported in interview that their children were showing higher levels of social interaction with their peers in the school setting. All the children, apart from William, attended mainstream school settings, and all of the children, apart from William, made gains (some greater than others) in their language skills, use of play and leisure time and/or interpersonal relationships on the Vineland-II. This finding is consistent with research that shows that children who are included in mainstream educational settings make greater gains on standardised measures of language and social competence than their peers in special education classes (Jenkins et al., 1989; Evans et al., 1992; Hunt et al., 1994; Harrower & Dunlap, 2001). It may be that including these children with autism in settings where social interaction is encouraged between all children has had an impact on this area of their development. Observational data of the children highlighted the differences in their willingness to interact with their peers at the two time points. Matthew, for example, was observed engaging in a turn taking game with another child during the secondary observation, whereas during the initial observation had only engaged in solitary play.

5.1.3.3 The impact on the family of a diagnosis of autism?

It was encouraging to find that 3 out of the 5 parents (2 in the EarlyBird group and 1 in the non-EarlyBird group) who were interviewed spoke not only about the negative impacts of a diagnosis of autism on the family, but also focussed on how their child with autism had positively impacted on their family. The negative impacts appeared to be restricted to the initial diagnostic period which was reported by four out of the five parents interviewed as distressing. It appears from the interviews that once parents had come to terms with their child's diagnosis and were able to learn how to support their child appropriately that they became more positive about their experience of having a child with autism.

Research on the impacts of autism on the child's siblings was discussed in the literature review. The semi-structured interviews with both groups of parents in this study highlighted that their child's autism had had a significant impact on their other children. Themes such as the sibling *'always being on the sidelines,' 'not being able to play with their sibling with autism,' 'not taking part in community activities'* and *'aggression directed towards them'* emerged. Consistent with the findings of Lobato (1985), siblings who were also in the pre-school years appeared to be more significantly affected than those who were older. This was demonstrated by parental reports. Of the children in this study, Jack and Matthew had siblings who were older, and it was reported that the impact of their autism was more positive, whereas Christopher, Rory and William had younger siblings, and their impact was reported to be more negative. Oscar did not have any siblings.

Jack and Matthew's parents both made more positive comments about the impact of their autism on their siblings, whereas the other parents spoke more negatively about how autism had affected their child's sibling. Additionally, Jack was the only child who had more than one sibling, which could have further impacted on his siblings' positive adjustment and acceptance of their brother. This is consistent with the findings of Miller

(2001), where it appeared that the impact of autism on siblings is reduced and there is better psychosocial adjustment in siblings where there are more children in the family.

This once again highlights the importance of considering the family context when designing interventions for children with autism. Factors such as whether the child has siblings, the siblings' ages, how many siblings they have and birth order may be important. The intervention that the child with autism is exposed to may affect the rest of the family and could additionally have far reaching effects for the child's sibling/s.

5.1.3.4 Which factors appear to be important in reducing the negative impact of a diagnosis of autism on the family?

Both groups of parents spoke about their need for support in the period following a diagnosis of autism. A component of the EarlyBird Programme that appeared to receive the most positive comments concerned the opportunity for parents of children with autism to meet together. Frequent reference was made to the opportunity to share experiences and the realisation that "we are not alone." Given the demands made on parents of children with autism, and the difficulties that can limit and reduce their social lives, there appears to be few opportunities for parents to meet. This can result in parents not meeting other children with autism or their parents, who have the potential to provide a valuable source of support.

The literature in this area shows that the social exclusion that parents of children with autism face can be a high risk factor for maternal depression (Bristol *et al*, 1993). Parents who did not take part in the EarlyBird Programme spoke about their need for support in the period following their child's diagnosis. William's mother, for example, stated "*I know I needed support but the most support I have had is off the NAS [National Autistic Society] forum.*" The support that parents received from the EarlyBird Programme appeared to give the EarlyBird group of parents greater confidence when

dealing with challenging behaviours. For example, Jack's mother reported that when she was out with him she prepared in advance using visual supports, in order to help her son cope with new experiences. This had helped their family to be included in the community again, as their son was coping better being out. The frequency of his challenging behaviour had therefore reduced when out in the community.

It would have been interesting in a larger study to have included a third group of parents and children where informal support and contact with other parents and their children with autism was encouraged. This would enable a more specific focus on the potential positive contribution of parents having the opportunity to meet and share experiences.

5.1.3.5 Challenges to access of the EarlyBird Programme?

The interviews with the parents from the non-EarlyBird group highlighted that there are a number of barriers to the access of early intervention services. The parents in the non-EarlyBird group who did not attend the 13-week EarlyBird Programme spoke about the practicalities of transport and child care as the main barriers to them taking part. The EarlyBird Programme is currently only run in one part of the county where the study took place, and parents who lived in the south of the county reported that it was too far to travel on a weekly basis. Additionally, one parent did not have access to her own transport and stated that getting to the programme using public transport was very time consuming and expensive for her. Although one parent reported that the programme offers child care at the centre where it takes place, the parents in the non-EarlyBird group were reluctant to leave their children in the care of people with whom they were not familiar. Additionally, they reported that due to their child's needs, specifically difficulties with coping with changes in their routines, it was not practical to leave their children in an unfamiliar child care setting.

The semi-structured interviews with the non-EarlyBird group of parents highlighted that there is currently a need for what they termed a 'live forum.' This was described as a local support group where parents could meet informally, but also include some professional support, specifically; Speech and Language Therapists, Educational Psychologists, Parent Partnership and Inclusion Consultants, with knowledge of autism and practical support strategies. Both groups of parents were aware that the support that they gained from professionals and other parents was invaluable, but due to the access issues discussed above the non-EarlyBird group of parents felt that they could not attend structured programmes such as the EarlyBird Programme, which required them to attend all the sessions. Additionally, parents in the EarlyBird group had attended other support groups, which they had heard about through attendance on the EarlyBird Programme. This has implications for this population of parents as some parents are receiving support in a number of different areas, whereas some are not.

5.2 SHORTCOMINGS AND STRENGTHS OF THE CURRENT RESEARCH

5.2.1 Participants

The distinct individual differences of the children in this study have made it impossible to compare overall patterns of development of the children in the study time period. Additionally, external factors such as family, school placement, and additional professional support have more than likely contributed to the individual patterns of development that were reported for all the children.

Differences in parental motivation could have been a factor that affected the reported changes in the children over the time period of the study. For example, the EarlyBird group of parents may have had higher levels of motivation at the start of the study. Prior to attending the programme parents had to be committed to attending weekly

sessions, carry out homework tasks and participate in home visits. In order for parents to take on these increasing demands in their lives there would have been a belief that at some level they would benefit from the programme. In addition participating in the programme could have resulted in a 'Hawthorne effect,' where improvements in the children's development reported by this group of parents could have been a result of the parents' awareness that they were being studied.

A second issue is that of support. Parents who did not take part in the programme spoke of 'child care' issues as one main reason for not attending the programme. It could, therefore be assumed that the parents in the EarlyBird group must have had some form of support in order for them to attend the programme. Having access to such support could mean that it is available at other times, meaning that these parents were not only receiving support through the EarlyBird Programme, but were also receiving additional support at other times. This may have resulted in lower levels of stress and feelings of exclusion and isolation overall, which could have impacted on their perceptions of change in their children over the time period of the study.

Finally, the fact that both parents could take the amount of time off from work in order to take part in the EarlyBird Programme suggests that these families are perhaps not under as much financial pressure as some other families who are unable to take part in such programmes. This could have an impact on the families overall stress levels, which may affect the way that the family views the impact of autism on the family. William's mother, who appeared to view his autism more negatively than any other families in the study, was the one mother who stated that she could not attend the EarlyBird Programme due to the financial pressure of transport costs.

5.2.2 Measures

The standardised measures, apart from the Early Years BAS II, relied on the parents completing rating scales and interview schedules in order to gain age equivalent scores of the children's functioning in the areas being explored, as well as autism severity scores on the GARS-2. Some studies have shown that parents tend to give higher estimates of their child's functioning than professionals (Stone & Rossenbaum, 1998; Freeman, Perry & Factor, 2007), although others have found that ratings are similar for both parents and professionals (Freeman, Perry & Factor, 1991). Due to the fact that two sets of data were gathered for the children over the time period of the study it can be assumed that if parents had rated their children too highly at the time of initial data collection, and then been more realistic at the time of secondary data collection, or vice versa, this would have had an impact on the developmental gains that were found for the children. Unfortunately, it was not possible to control for this phenomenon due to the nature of the measures that were used, which relied on the rater having a good knowledge of the child across a number of contexts.

There were contradictions in the scores on three of the measures used for two of the six children in the study, where increases on scores on the Vineland-II did not match the other measures that were used. For one child, Oscar, behavioural observations were not available at the second time point in order to inform whether the Vineland-II or the GARS-2 was inaccurate. Matthew's score for expressive language did not increase on the Vineland-II, whereas it was clear on the GARS-2 that there was improvement in his communication over the time period of the study. This was also supported by observational and interview data. It appears that for Matthew, the Vineland-II did not accurately measure the improvement in his expressive language skills. This highlights the importance of gathering multiple sources of data from different measures in order to attempt to be as accurate as possible when reporting results.

The researcher was unable to gain SDQ data for 'teacher ratings' for the children in the study due to all the children changing educational placements during the time line of

the study. It would have been interesting to have had teacher ratings of the children's behaviour in order to compare their perceptions of changes in the children with the parent's ratings on the SDQ. One main criticism of the SDQ from the parents in this study was that the statements on the SDQ were not appropriate for this age-group of children. They reported that 'normal' developmental challenges had not been taken into account, including issues, such as that which the parents termed 'the terrible twos,' which parents felt had been pathologised on the SDQ for this age group, rather than normalised. Additionally, the SDQ form for this age group of children does not appear to have standardisation norms or reported reliability and validity information. Therefore, the results of the SDQ should be interpreted with caution.

Although the Vineland-II was standardised on an American population, it has been used in a number of UK studies (Charman, et al., 2004; Martin et al., 2003 Pine et al., 2006) and has been found to be a 'useful' measure of developmental progress where parents could be used as informants. It has been noted that the Vineland-II is one of the most commonly used tools in the UK both prior to and following statutory assessment (Martin et al., 2003) of children with autism, and that this assessment of adaptive behaviour is highly correlated with cognitive ability scores. In this study the Vineland-II did not correlate with all of the other measures for all six of the children. Therefore, the results need to be interpreted with caution. However, similarities in developmental change were found to correlate for four of the six children. None of the parents included in the study reported that it was difficult to complete or that there were items that they could not understand. It therefore appeared that in this study, with this group of parents the items included in the Vineland-II were culturally relevant.

The British Ability Scales-II does not include standardisation norms for children with autism. Unfortunately, this is the case for all psychometric tests of cognitive ability in the UK. However, a working group established to advise on a consistent approach to early intervention in 1999 set out to highlight what would be good practice in terms of

initial assessments of the young children concerned and of gaining baseline data by which to measure change over time. The BAS-II was included as a good measure of cognitive ability, although it was highlighted that tests of intelligence on this population of children should be interpreted with caution (Connor, 1999). In this study the variability in the children's initial and secondary test scores (where two sets of data are available) on the BAS-II further highlights this issue. Individual and environmental factors cannot be ruled out when interpreting their results. However, the researcher has highlighted in Chapter 3 that the BAS-II has been used in a number of UK studies with children with autism as a measure of cognitive ability (Reed, Osborne, Cornees, 2010; Keen & ward, 2004; Martin, Bibby, Mudford, Eikeseth, 2003).

The incorporation of a range of measures which have reliability and validity data, in order to answer the different research questions is one of the strengths of this study. This enabled the researcher to explore individual patterns of development of pre-school children with autism, parental experiences of having a child with autism, as well as the perceptions of those parents who participated in the EarlyBird Programme and those who did not. The researcher was initially concerned that the amount of time it took parents to complete the standardised questionnaires would be off-putting, although when questioned, parents reported that completing the standardised questionnaires had been somewhat 'therapeutic,' as it gave them time to step back and view their child from a different perspective.

Additionally, the qualitative interviews provided a valuable source of information about the impacts of the child's autism on the family, which would not otherwise have been gathered through the use of standardised measures alone. The researcher also believed that by incorporating semi-structured interviews into the study, parents would feel that the researcher had a genuine interest in what they had to say, their personal experiences and future aspirations for their child. By not involving the parents in the study they could have felt that their opinions and views were less valued, which in turn

could have exacerbated the perception that some professionals do not take the time to listen to them, as well as the perceived belief that professionals think that parents are to blame for their child's difficulties.

Although the observations of the children by the researcher were informal in nature they were still valuable in the context of this study. Parental reports of development in areas such as social interaction could be compared to behaviour observations. Additionally, the opportunity to observe the children twice before interviewing the parents may have made the parents feel that the researcher had a genuine interest in their children. This could have helped to develop rapport between the parents and the researcher, which may have lead to the parents feeling comfortable to talk to the researcher about their feelings and emotions and private issues in their family, such as how they dealt with their child's diagnosis, with more confidence.

5.2.3 Design

Having a larger sample of participants would have been preferable, although there were not enough families within the context of the study who were willing to take part in the EarlyBird Programme. The researcher attempted to recruit participants from surrounding local authorities, but due to their substantially different start dates for the programme, this was not possible. However, as Jordan (1999) states, although there are many difficulties inherent in the practical situation of conducting research there are also advantages. The biggest of which is that issues are likely to be real ones that affect the daily lives of people with autism and their families, and the results are also likely to have a direct affect on practice. Jordan (1999) concludes in her review that,

"Research is not, or should not be, an activity carried out by an elite, using natural settings merely as sources of data. It should be a process that all practitioners are engaged in at some level, to improve practice and make decisions on a rational and informed basis" (pg. 432).

The distinctive individual differences of the children in the study meant that the utilisation of a multiple case study design was appropriate. An alternative design would have been to include a third group of parents and their children in the study who could have received a form of informal support through a support group. It would have been interesting to ascertain whether parental support through informal means would result in similar parental reports.

In terms of the current 'gold standards' that have been set with regards to autism research, the current design will perhaps be viewed as weak rather than strong. Systematic reviews, such as those by Matson (2007) and Jordan et al. (1998), recommend large-scale randomised controlled studies in order to maximize the validity of the results and increase generalisability to a larger population. However, the researcher argues that the current design has strengths, such as the value of the qualitative data that were gathered, which has highlighted that this population of children are indeed not homogenous, and should, therefore, be treated as individuals with individual intervention plans.

An implication of case study research, which has been highlighted by Gerring (2007), is that future researchers aiming to replicate and extend studies benefit from case study research. This is due to the fact that it may highlight useful areas to pursue. Although one cannot generalise from this small scale work it does contribute to a growing body of literature from which it might be possible to generalise in the future. This is especially true if more case studies were undertaken in the future to combine with these data.

One further criticism of the case study design is that the individual who is the subject of the case study may not be representative of the population. Nonetheless, Stake (2010) states that although a 'typical' case does work well, it is often the unusual cases that help to illustrate matters that we can overlook which add value to the research and

extend studies in the future. However, in studies where individuals have autism there does not appear to be a 'typical' case on which to base case study research.

5.3 IMPLICATIONS FOR PROFESSIONAL PRACTICE

This research study has implications for professional practice and provides a distinct contribution to the field of Educational Psychology. The exploration and measurement of patterns of development in pre-school children has not been documented in the literature. There are limited longitudinal studies, which provide retrospective accounts of children's development over long periods of time, although such studies are outdated and do not include standardised measures of development over short periods of time.

The majority of professionals who are required to make decisions about appropriate support and educational provision for these children are expected to do so after a 'snapshot' of time in the child's life. Exploring the child's development using such measures as those that were used in this study does not, and often cannot, occur due to the pressures that professionals are under to make decisions about funding and educational provision soon after meeting the child. In the Local Authority where this study took place the children in question are often below the age of two years six months and decisions about future school placement at the age of four years are already being made.

If further studies, such as this one, were undertaken in order to document developmental trajectories of children with autism in the early years, there would be an evidence base that could encourage parents and professionals to give the child in question time to mature. This would allow the developmental gap between him and his

'typically' developing peers to begin to close, before decisions were made about school placement. More informed decisions, based on the child's developmental levels at the time of entering formal school provision, rather than their levels at the time when assessment first took place, could occur. This would ensure that the child was correctly placed and that optimal levels of targeted support could be provided in order to encourage further development.

The implications of the 'Autism Grief Cycle' (Sicile-Kira, 2004) and 'resolution of diagnosis' (Pianta and Marvin, 1993) on the child's development have not been explored in current literature with regards to autism and how this may have an impact on the child's development overall. It is possible that the sooner the parents come to terms with their child's diagnosis, the sooner the parents are able to improve their interactions with the child, therefore harbouring a nurturing and healthy attachment status, which could impact on the child's interactions. Additionally, providing supportive environments could help parents gain the knowledge and skills they need to help them respond to their child's needs earlier.

It is important that professionals become more attuned to the needs of the parents when making a diagnosis, rather than focussing only on 'within child' factors. This is currently the case due to individuals within the medical profession making the diagnosis. Other factors, such as parental reaction and the stress that the diagnosis may cause need to be taken into account when a diagnosis is made. The inclusion of such factors into some type of 'diagnostic protocol' may encourage professionals to direct parents towards appropriate support immediately, rather than them having to deal with the initial shock of the diagnosis alone and only seeking support once they have started to come to terms with their child's diagnosis.

Additionally, professionals need to become more aware of the impacts of a diagnosis of autism on the family, and familiarise themselves with the 'Autism Grief Cycle' (Sicile-

Kira, 2004) and the implications that this may have for the entire family. Maternal depression in this population has been well documented (Freeman, Perry & Factor, 1991; Hastings & Johnson, 2001); however the mental health status of the mother does not appear to be taken into account when designing interventions for this population of children. Maternal depression does not only have an impact on the child with autism, but has implications for marital discord, sibling adjustment and family emotional well-being (Rivers & Steoneman, 2003).

All the parents who took part in the study highlighted the need for less formal types of support, what some termed a 'live forum.' All parents were aware of the importance of support, but the level of commitment required to take part in any formal intervention programmes, such as the EarlyBird Programme, which would provide them with support, was often beyond what they felt they could agree to. This was not only due to the needs of their child with autism, but also because of their other children, whose routines would be disrupted if they were to take part. Additionally, due the size of the county in which the research took place, the distance that parents would have to travel in order to take part in the programme was far. Providing local support groups was a preferred option and parents felt that this would then be more accessible to them. Such local support groups would also help parents to form a network of friends living in the same area who also have children with autism. This would provide an additional level of support, and given that social exclusion and loneliness is often reported as a significant factor that may increase levels of maternal depression, could help mothers to feel less secluded and more able to take part in community activities.

Finally, the implications of special school placements should be explored further. William attended a special school on the basis of being 'non-verbal.' The results of the cognitive assessment showed that he scored within the 'Below Average' range at the second time point, which would, if educational labelling were to be used, not put him in either the moderate or severe learning difficulty ranges. He was the only child in the

study that regressed, which is a concern, as this finding is in line with the literature (Jenkins et al., 1989; Evans et al., 1992; Hunt et al., 1994; Harrower & Dunlap, 2001), which highlights the potential benefits of including this group of children in mainstream education where they can learn more appropriate social skills, communication and behaviour from their peers without autism. Much of a child's learning at this age is based on modelling and copying, which in a mainstream environment could be highly beneficial. The child with autism's copying of their peer's behaviours and interactions could help to reduce inappropriate behaviour and increase social interaction. On the other hand, a child who is placed in a special school may not be exposed to such positive peer models due to many of the other children in the setting having similar difficulties with communication, social interaction and behaviour. It is therefore not possible to encourage peer interaction if a large proportion of the children within the setting also have difficulties in these areas of their development.

Early parental support and intervention in the authority where the study took place does not appear, at this stage, to be including a wide range of children with autism from different socio-economic backgrounds. In the current study it was clear that the families involved were from fairly affluent backgrounds and appeared not to have additional stressors associated with the financial burdens of having a child with autism. There are a number of possible reasons that children from less affluent backgrounds are not being included in such programmes. Firstly, they may not be identified as having autism as early as their affluent peers due to their parents not being as assertive in securing appropriate assessments. Secondly, parents opt out of being involved in formal intervention programmes due to work commitments, or the resources that are required to take part in programmes, such as child care and transport costs. These children are, therefore, at risk of becoming more vulnerable as they get older, due to challenging behaviours and limited communication, which may lead to an increased need to access special educational placements. This could lead to greater burdens on their families and on society as these children require more funding throughout their life

time than those that are perhaps receiving support earlier. It is therefore essential that professionals work together to attempt to identify ways in which support can be offered to more families, taking into account issues such as transport costs and child care that hinder access to support programmes. This could lead to increased early intervention and support for vulnerable children and their families who might otherwise fall through the net.

5.4 IMPLICATIONS FOR FUTURE RESEARCH

A range of measures were used in this study as it has been suggested that researchers in this area should consider using standardised measures of cognitive, language, social and adaptive abilities and measures of rates of developmental change. In this study the Vineland-II, SDQ and BAS-II were used in order to attempt to address this. Matson (2007) states that core tests of autism, such as the Childhood Autism Rating Scale (CARS) and Autism Diagnostic Observation Schedule (ADOS), are rarely used as pre-test post-test assessments and should be considered, as this would allow for direct comparison across programmes. In this study the GARS-2 was used, although the researcher believes that a more robust measure, such as the ADOS, would provide finer detail about change in autism symptomology, and should be considered in future studies.

The current study has a number of implications for future research. Firstly, it would appear that further research documenting the differing developmental trajectories of this group of children will be of value to both researchers and practitioners and may help disentangle maturation from treatment gains.

Secondly, the Vineland-II appeared sensitive to changes in the children's development over a short period of time. Due to the difficulties inherent in assessing this group of children, having a robust parental report measure, such as the Vineland-II, is essential.

The Vineland-II's predecessor, the VABS, was also reported in the Hardy (1999) study as '*robust*' and able to report the same measures of communication as a standardised communication assessment had. However, in this study it is unclear whether the Vineland-II was in fact a reliable measure, as contradictions in scores on the different measures for two of the children were highlighted. This raises specific concerns when the different assessment measures were measuring similar constructs, for example, social interaction and/or communication. The researcher recommends that future researcher be mindful of this when interpreting the results of this measure, and where possible, multiple sources of data should be used in order to enhance the rigour of the research.

Few studies report the perceived child outcomes across various developmental areas, including communication, cognition and socialisation, as determined by family members. Outcomes are typically reported through the use of standardised tests and professional observations (Rogers, 1996), yet there is little information about family perception of child-outcomes derived from publicly funded early intervention programmes (Dillenburger, Keenan, Gallagher & McElhinney, 2004). It has been recommended (Kohler, 1999) that future research examines the perceived outcomes and social validity of the specific interventions by parents and family members of the children taking part. Involving parents in this study by gaining their views through methods such as interviews should therefore be essential in any research studies involving this population of children and their parents. Ensuring that parents have a voice and feel that their '*expertise*' is valued will lead to parents being more willing to take part in early intervention studies, as well as add to the social validity of the early intervention in question. Any research in this area involves the parents using their time, energy and sometimes other resources to take part. They need to feel that they are valued and gain an understanding of how their involvement can have positive implications for their child. The more valued a parent feels, as is the case with this study due to the researcher including the parents' views through semi-structured

interview, the more willing they will be to put extra time into ensuring that their child is fully taking part in the early intervention. This could have significant impacts on the results of early interventions studies.

Matson (2007) states that it is crucial that control groups be used, and where possible participant matching and random assignment be followed. However, it is clear from the current study that the heterogeneity of this population of children makes this an almost impossible task for any researcher.

CHAPTER 6

CONCLUSION

The main focus of the study was to explore individual patterns of development in the children and factors that may have contributed to reported changes in the children's development over the study time period. Additionally, the experiences of five of the six participating parents and their views on the impacts of a diagnosis of autism on the families were explored, and where these impacts were reported as being negative, the researcher aimed to explore the factors that had helped the families to become more positive and to cope better with their children.

This study provides a distinct contribution to the field as in-depth case study research exploring individual patterns of development of pre-school children with autism have not been documented in the literature. There are limited longitudinal studies, which provide retrospective accounts of children's development over long periods of time, although such studies are outdated and do not include standardised measures of development over short periods of time. One of the important findings of the study was that five of the six children showed positive developmental changes that were greater than expected in one or more aspects of their development over the period in which the study took place. This finding is significant as a greater understanding of the developmental trajectories of this group of children in the early years could impact on the way that children are assessed by professionals over time. This could also help those charged with providing specialist provision for children with autism in local authorities make more informed decisions about specialist support based on individual developmental profiles. Additionally, if the research base in this field continues to be built upon by future researchers there would be a greater ability in the future to

disentangle maturation gains from treatment gains where early intervention programmes are being evaluated.

Due to the heterogeneity of the group, which included specific personal, family and school factors, as well as differing levels of professional support, it is unclear which specific factors are more or less important in encouraging development in young children with autism in the period following a diagnosis. However, this study has explored a number of factors that could have impacted on their development and therefore could contribute to a growing body of knowledge and future case-study research. Such research could help to highlight the factors that are more or less important in encouraging development for this population of children. This study therefore makes a distinct contribution to the expanding research base in this field.

All the parents included in the study recognised the need for some form of parental support in the period immediately following a diagnosis of autism. The parents who had received such support through the EarlyBird Programme spoke positively about it, and the parents who had not managed to access support through the programme suggested that local informal support groups would be beneficial. Such support would not only provide a forum for parents to discuss difficulties that they were experiencing with their children, but it would also provide them with the opportunity to socialise with other parents and their children which could help in reducing their reported levels of social exclusion.

Additionally, challenges to accessing the EarlyBird Programme need to be addressed within the Local Authority where the research took place. Issues such as transport and child care could mean that vulnerable and less affluent families are not able to access the support that is being provided by the Local Authority. If this is indeed the case alternative forms of parental support at a more local level could be more beneficial to a larger population of parents and their children with autism. The support given and

intervention programme that is devised should ideally be matched to the individual child and their family.

The heterogeneity of this population of children was once again highlighted through this research, and should not be discounted. The heterogeneity of the family unit needs to be taken into account and factors such as siblings (their age, gender and birth order) economic status, and locale should be at the forefront of professionals' minds when attempting to support this population of parents and children.

Finally, this research highlights the needs for an ecosystemic model of service delivery for all professionals working with this population of parents and children, where the child, the family and other contextual factors are explored, in order for professionals to provide the parents and the child with optimal levels and types of support.

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APPENDIX 1

DSM-IV CRITERIA, PERVASIVE DEVELOPMENTAL DISORDERS

DSM-IV Criteria, Pervasive Developmental Disorders

299.00 Autistic Disorder

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
1. qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
 2. qualitative impairments in communication, as manifested by at least one of the following:
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 3. restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
 - d. persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

299.80 Pervasive Developmental Disorder, Not Otherwise Specified

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" --presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

299.80 Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - 1. marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - 2. failure to develop peer relationships appropriate to developmental level
 - 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - 4. lack of social or emotional reciprocity
- B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - 2. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - 4. persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

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APPENDIX 2

ETHICAL APPROVAL

Appendix 6: BPS Ethical Approval Form

STUDENT RESEARCH ETHICS APPROVAL FORM Psychology & Human Development

This form should be completed with reference to the BPS Code of Ethics and Conduct – available online from www.bps.org.uk

On which course are you registered? Doctorate in Professional Educational, Child and Adolescent Psychology

Title of project: The National Autistic Society's EarlyBird Programme: An evaluation of the impact of a parent training programme on the cognitive ability, communication, social interaction and challenging behaviour of pre-school children with Autistic Spectrum Disorder.

Name of researcher(s): Louise McCauley

Name of supervisor/s (for student research): Mary Parker and Vivian Hill

Date: 13.01.09 Intended start date of data collection (month and year only): 04/09

- 1. Summary of planned research** (please provide the following details: project title, purpose of project, its academic rationale and research questions, a brief description of methods and measurements; participants: recruitment methods, number, age, gender, exclusion/inclusion criteria; estimated start date and duration of project). It's expected that this will take approx. 200–300 words, though you may write more if you feel it is necessary. Please also give further details here if this project been considered by another (external) Research Ethics Committee.

The National Autistic Society's EarlyBird Programme: An evaluation of the impact of a parent training programme on the cognitive ability, communication, social interaction and challenging behaviour of pre-school children with Autistic Spectrum Disorder.

Rationale: As a recently developed early intervention parent training programme, effectiveness data and information about the impact of the EarlyBird Programme on child outcomes have not been documented. Additionally the two documented efficacy studies (Hardy, 1999; Shields & Simpson, 2004) use only one standardised measure when evaluating the programme, reducing the possibility of direct comparison with other early intervention programmes. Child outcomes have not been measured, which, if comparison with other early intervention programmes was to take place in future, is essential.

Research Question: Does parent participation in the EarlyBird programme contribute to improved communication, social interaction and behaviour of pre-school children with ASD?

Hypotheses

- 1) Pre-school children with ASD will show improvement in both expressive and receptive language skills following parent participation in the EarlyBird programme.
- 2) Pre-school children with ASD will show improvements in their social interaction with peers

and parents following parent participation in the EarlyBird programme.

- 3) Pre-school children with ASD will show improvements in behaviour, which includes the reduction of challenging and inappropriate behaviours following parent participation in the EarlyBird programme.

The participants will consist of pre-school children (<4) with a diagnosis of ASD. All children would have been diagnosed by an external practitioner. At this stage the number of participants has not been confirmed, but will be within the range of 16 to 20 children. The following information will be collected for each participant:

1. Age
2. Gender
3. Ethnicity
4. Primary language
5. Socio-Economic Status
6. Parent's education history
7. Special and Additional Educational Needs
8. Locale (urban, rural, suburban)
9. Diagnosis
10. Concurrent or historical intervention exposure

The parents of the children will be asked to fill in questionnaires.

Measures

BAS II Core Scales – Early Years (Elliot, 1996)

SDQ parent and teacher reports (Goodman, 1997)

Vineland Adaptive Behaviour Scale (Sparrow et al, 1984)

Structured Observations

Dates: March 09 – March 2010

- 2. Specific ethical issues** (Please outline the main ethical issues which may arise in the course of this research, and how they will be addressed. It's expected that this will require approx. 200–300 words, though you may write more if you feel it is necessary. You will find information in the notes about answering this question).

An information sheet outlining the details of the study, its design and purpose will be included with the consent forms. This sheet provides the parents with information as to why the study is taking place, why they have been selected to take part, how their children will be assessed, and what will be done with the results. Parents are also informed of their right to withdraw at any time. The researcher will ensure that parental consent is gained for all participants. Ethical consent will also be gained from the university ethics department as well as the local authority in which the research is taking place. Where observations will take place consent will be gained from the parents and

teachers of the pre-schools, if the children are attending such institutions. All participants will be assigned numbers for identification so that their identities are kept confidential. The researcher will ensure that all data collected will be stored in a locked fire proof safe. Only the lead researcher will have access to this cabinet. The parents will be informed of the results of the assessment of their child and information will be shared in a professional and sensitive manner. The EarlyBird programme directors and the parents will have the findings of the research shared with them. If the research was to be published all participants would be informed. The researcher has a current and up to date CRB due to the nature of employment as a trainee educational psychologist.

3. Further details

Please answer the following questions.

		YES	NO	N/A
1	Will you describe the exactly what is involved in the research to participants in advance, so that they are informed about what to expect?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Will you tell participants that their participation is voluntary?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Will you obtain written consent for participation?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	If the research is observational, will you ask participants for their consent to being observed?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Will you tell participants that they may withdraw from the research at any time and for any reason?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have ticked **No** to any of Q1-8, please ensure further details are given in section 2 above.

		YES	NO	N/A
9	Will your project involve deliberately misleading participants in any way?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
10	Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If Yes , give details on a separate sheet and state what you will tell them to do if they should experience any problems (e.g. who they can contact for help).	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
11	Will your project involve human participants as a secondary source of data (e.g. using existing data sets)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

If you have ticked **Yes** to any of 9 - 11, please provide a full explanation in section 2 above.

		YES	NO	N/A
12	Does your project involve working with any of the following special groups?			
	• Animals	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	• School age children (under 16 years of age)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	• Young people of 17-18 years of age	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	• People with learning or communication difficulties	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- | | | | |
|---|--------------------------|-------------------------------------|--------------------------|
| • Patients | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| • People in custody | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| • People engaged in illegal activities (e.g. drug-taking) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |

If you have ticked Yes to 12, please refer to BPS guidelines, and provide full details in sections 1 and 2 above. **Note that you may also need to obtain satisfactory CRB clearance (or equivalent for overseas students).**

There is an obligation on the Student and their advisory panel to bring to the attention of the Faculty Research Ethics Committee any issues with ethical implications not clearly covered by the above checklist.

APPENDIX 3

INFORMATION ON THE STUDY

Study Title:

The National Autistic Society's EarlyBird programme: An evaluation of the impact of a parent training programme on the cognitive ability, communication, social interaction and challenging behaviour of pre-school children with Autistic Spectrum Disorder.

Dear Parent,

You and your child are being invited to take part in a research study. Before you decide whether or not to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The research study aims to examine the effects of an autism specific early intervention parent training programme on the cognitive ability, communication, social interaction and challenging behaviour of pre-school children who gave a diagnosis, or are awaiting a diagnosis of Autistic Spectrum Disorder (ASD). In particular, the main aim is to examine whether early intervention by parents is effective in improving child outcomes in two areas of functioning, namely communication and social interaction and overall cognitive ability, as well as behaviour, which has been highlighted as the main barrier to effective inclusion of children with ASD in mainstream schools.

Design of the Study

All the children who take part in the study will be assessed in four areas, namely cognitive ability, social interaction, communication and behaviour, before parents start taking part in the EarlyBird programme. The children will then be reassessed using the same measures 6 months later, once parents have completed the programme. Another group of children whose parents will take part in the programme at a later date, or who have decided not to take part at all, will form the 'comparison group.' These children will be assessed in the same way before their parents take part in the EarlyBird Programme, The purpose of this is to see whether any positive changes that do occur are indeed due to the programme. If you agree to participate your child will fall into either the 'experimental' or 'control' group, depending on when you are taking part in the EarlyBird Programme. Your name and your child's name will never be used in the study. If you agree to take part you and your child will be assigned a 'participant identification number' to make sure that all your information is kept confidential.

Why have I been invited to participate?

You have been invited to participate as you will be taking part in the EarlyBird programme. The programme is relatively small and very few participants take part over the year due to the nature of the programme and the age of your child. This research is important as the more evidence that we have about the effectiveness of programmes for children with autism will mean that over time more effective early intervention can be provided for families while their children are very young. We are hoping to invite approximately 32 children and parents to take part in the research study.

Do I have to take part in the study?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and will need to sign the consent form that is attached. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I decide to take part?

If you decide to take part and sign the consent form the lead researcher will be in contact with you shortly to arrange a time and place that is convenient for you to meet. The researcher will come to you to assess your child and you will not have to go out of your way for this to happen. The assessment can take place at the Children's Centre, at a pre-school or even in your own home. You will also be asked to fill in 2 short questionnaires before and after you have completed the programme. The assessment of your child should not take more than 45 minutes.

What are the possible benefits of taking part?

Taking part in the research study will be of benefit to you, and children in the future. You will be informed of the progress that your child has made and you will receive a short report and explanation of the results of the assessment of your child. You will also have access to the completed research study. It is important for research like this to take place so that in future parents are able to make informed decisions about which programmes are effective for children with autism, and whether they feel they would like to take part.

What will happen to the results of the study?

The results of the study will be used as part of a Doctoral Thesis. If the research was to be published at any point you would be informed of this. Your information and details would never be published. All participants will be sent a copy of a 'research brief' which summarises the findings of

the research once completed. If you required any more detailed information you can contact the researcher.

Who is organising the research?

The research has been organised by a trainee educational psychologist who works for Buckinghamshire County Council's Educational Psychology Service and is completing a doctoral programme at the Institute of Education in London.

Contact for further information

If you require any more information before making a decision please could you contact:

Louise McCauley at either lmccauley@buckscc.gov.uk or 01296 383219 (Educational Psychology Service)

Thank you for taking time to read the information sheet.

APPENDIX 4

CONSENT FORM



Leading education
and social research
Institute of Education
University of London

CONSENT FORM

Full title of Project:

The National Autistic Society's EarlyBird Programme: An Evaluation of the impact of a parent training programme on the cognitive ability, communication, social interaction and challenging behaviour of pre-school children with Autistic Spectrum Disorder.

Name contact address of Researcher:

Louise McCauley: Buckinghamshire Educational Psychology Service lmccauley@buckscc.gov.uk 01296383219

Please Initial Box

- | | | |
|----|--|--------------------------|
| 1. | I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. | <input type="checkbox"/> |
| 3. | I agree to fill in the questionnaire/s given to me before and after the study. | <input type="checkbox"/> |
| 4. | I agree for my child to take part in the study and to be assessed before and after the programme is completed. | <input type="checkbox"/> |
| 5. | I agree to take part in the above study. | <input type="checkbox"/> |

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

APPENDIX 5

INFORMATION SHEET ABOUT THE CHILD AND FAMILY



Dear Parent

Please could you fill out this information sheet? Please do not leave any section out.

Name of Child	
Date of Birth	
Gender	
Ethnicity	
Primary language spoken	
Socio-economic status of parents (earning per household per annum)	£
Parent's educational history	GCSE A-Level Tertiary Education Post-graduate Education Other.....
Special and/or additional needs of child	
Where do you live? (Please circle)	Urban / Rural / Suburban
Child's diagnosis	
History of child's education	
History of any other interventions	
Does your child take any medication?	Yes / No If Yes please give more information

Thank you

APPENDIX 6

EARLYBIRD POST PROGRAMME QUESTIONNAIRE

NAS EarlyBird Plus: Post-programme Questionnaire

POST-PROGRAMME QUESTIONNAIRE

Name of team member _____ Date: _____

Child's name _____ Age: _____

Please take the time to fill in this questionnaire,
which will help us to monitor the programme.

1a) What have you learned about autism whilst participating in the programme?

1b) How will this help you in the future?

2a) What have you learned about communication whilst participating in the programme?

2b) How will this help you in the future?

3a) Have you changed the way you communicate with the child?

Yes No

If yes: how?

3b) Have you noticed change in the child's communication?

Yes No

If yes, please describe:

4a) What have you learned about behaviour whilst participating in the programme?

4b) How will this help you in the future?

5a) Do you feel more confident about managing the child since participating in the programme?

Yes No

5b) Why?

6a) Would you recommend this programme to other parents and professionals?

Yes No

6b) What would you tell them?

NAS EarlyBird Plus: Post-programme Questionnaire

7. Has participating in the NAS EarlyBird Plus Programme helped everyday life with the child? Yes No
If yes: how?
8. Have you been helped by meeting and working with other parents and professionals at NAS EarlyBird Plus? Yes No
If yes: how?
9. Have you been able to share information and ideas from the NAS EarlyBird Plus programme with other people? Yes No
If yes: how?
10. Any other comments?
(Programme book / Video clips / EarlyBird professionals / etc...)

Thank you for completing this questionnaire.
Please return it to Sue Bayliss or Carol Morgan.

APPENDIX 7

SEMI-STRUCTURED INTERVIEW SCHEDULE



6 Month Post Intervention Parental Interview (E and C groups).

All Interviews to be tape-recorded and transcribed at a later date.

These questions are a guide.

1. Can you describe what your child was like 6 months ago when we first met?
 - Behaviour
 - Communication
 - Socialisation

2. What aspects of your child's needs do you think, as a parent, were most difficult to cope with?

3. When did you first become concerned about your child?

4. What did you do then?
 - time frame
 - number of professionals involved
 - alternative support

5. When were you first referred to the EarlyBird Programme?

6. Had you heard about it before?

7. What did you do then?

Took it up – continue with question 8.

Did not take it up- skip to question 12.

EB Parents

8. What were your expectations about the EB programme?
9. Could you give me an overview about the programme and what you found most valuable?
10. Why was this most valuable aspect of the EB programme?
11. What did you find least valuable?
12. Have you learnt anything at EarlyBird that you think you would not have learnt at your child's nursery school?

Continue to number 16.

Parents who did not take up EB Programme

13. What were the main reasons that you decided not to participate in the EB Programme?
14. Do you think that there are ways to increase the parental participation in such a programme?
15. What would have helped you as a parent to make a decision to take part in the programme?

All Parents

16. Are there alternative interventions that you would have preferred for your child?

17. If yes – what and why?

18. Over the past 6 months how do you think your child has changed?

19. Where in their development do you think that they have made the most gains?

20. What do you think that these changes are a result of?

21. How would people who know you well describe your character?

22. How would you describe yourself as a parent?

-calm, relaxed, anxious

23. How would you describe yourself as a person?

24. Is this different from how you would have described yourself 6 months ago?

25. What do you think has changed the way you describe yourself?

26. How do you think having a child with autism has impacted on family life?

-positive

-negative

-siblings

27. Do you view your child differently now than you did 6 months ago?

If yes – what has changed?

If no – why do you think that is?

28. Where do you see your child in 2 years?

29. Have you had any contact with autism lobby groups since your child was diagnosed?
-if yes, who, what support did they provide, what was the reason for contacting them?

APPENDIX 8

TRANSCRIPTION OF AN INTERVIEW



6 Month Post Intervention Parental Interview (E and C groups).

All Interviews to be tape-recorded and transcribed at a later date.

These questions are a guide.

1. Can you describe what your child was like 6 months ago when we first met?
 - Behaviour
 - Communication
 - Socialisation

He had a lot, um, not as much verbal communication skills. His vocabulary was not that big, 6 months does not seem a long time, but he is saying a lot more in this time. He is saying so much more stuff that he would not have said 6 months ago. Behaviour wise he is more defiant that he was, he will say no and has preferences of what he would like to wear now. He has got more ability to put his clothes on. We were dressing him then. It might be, um, he goes into school without me now. He is always pleased when I come to pick him up, but I think he likes that contact, a bit of a mummy's boy!

2. What aspects of your child's needs do you think, as a parent, were most difficult to cope with?

Um, his speech, or his lack there of, things that he needed or wanted to do was really trying, He was unable to express himself, like when I was giving him a snack and he wouldn't take it but would shout and run away. That was really trying, it dawned on me that he didn't understand or I wasn't giving him the right thing. I would then put him up on the counter and he could help himself.

3. When did you first become concerned about your child?

Quite early on, we already knew that there were problems with his siblings, one had speech problems and still does. As time went on he was not reaching certain milestones, he didn't walk until he was about 16 months, He was very late with all that, then of course words, they weren't coming when they should have, The paediatrician was becoming concerned. He was about 2. We had taken his sibling to a hospital in so we got involved with the big genetics study after the diagnosis for The girls were not diagnosed till after It was because he was a boy and they picked it up quicker.

4. What was the time frame between your concern and diagnosis?

Um, not long actually, um, as he approached 2 we knew that there were certain problems, which we were more aware that there were problems. So when he had his 2 year check up

the paediatrician said he was concerned and it all started from there, perhaps a matter of a year or so.

How many professionals were involved?

Um, well there was the paediatrician who diagnosed him; we then went to [redacted] we had a geneticist, an OT, a psych person and a SALT, um at least 5 people. It was a lot but you need to cover all the bases. We pretty much saw every one we could see. It was great because we had some good reports that we could bring over here. It became clear that we could not stay in [redacted] because there is not an infrastructure, the schools did not want to know, they didn't do special needs. We were stuck in the government system which was diabolical. We decided to come here then. Fragile X is a solid diagnosis that the professionals are aware of here and things can be done. I was really angry about the system there and wanted to march up to parliament's door with banners and so on, but it became clear that my kids don't have time for all that. I was also working full time which meant that I didn't have time to give to them. We knew of the fragile X society the NAS was all over here and we needed the support really and people who knew what they were talking about. So we came here.

5. When were you first referred to the EarlyBird Programme?

Um we were told about it by his nursery. Um, well just after he started there. So we have been here for about 18 months. There was a lady called [redacted] who came to see [redacted] and she mentioned it, and [redacted], his teacher too.

6. Had you heard about it before?

No

7. What did you do then?

Um, someone sent me something which I signed and sent off and then we started the programme in May.

Took it up – continue with question 8.

Did not take it up- skip to question 12.

EB Parents

8. What were your expectations about the EB programme?

Well, first of all I wanted to meet other parents and I know that this is run by the autistic society and there is a large crossover between autism and fragile x. Um, although people

don't really talk about autism and mention fragile x, I don't know why. There is a growing recognition though that people with autism should be tested for fragile x because the 2 could go hand in hand, I was hoping to meet people, get strategies and bounce ideas off others. I got what I wanted really. I met some great people, and um, I learned a lot of things about how my kids think and I learnt a lot of strategies. I bought a laminator; I was laminating cards to help with routine and stuff. I found it really helpful, the videos and stuff. Yeah, I found it really helpful.

9. Could you give me an overview about the programme and what you found most valuable?

Most valuable, um, well the overview was so that we could talk about what our challenges are. They have a book where they go through behaviours and stuff and sequencing and all that. The most useful was the strategies, the practical stuff. Sand timers and routine and things like that. There were a lot of things that I was hearing about that other people were dealing with, which I was not and it helped to give me back my perspective. Um, yeah when you are having less issues it does give you a sense of perspective back. There was a lady there actually, she didn't complete the programme but she came for the first few sessions, I think she had child care problems or something. Um, well yeah we were introducing ourselves the first day and she said, um, she is just amazing. I remember she said, hi my son is four and he has autism and it's not a problem. I remember thinking, what do you mean it's not a problem, it **is** a problem, and she says the more that you start seeing it like that, you get depressed and you get into the mindset that it is a problem and if you always see that negative side of it, it weakens you and you can't deal with it properly, which was basically what she said. I went up to afterwards and said wow! It is so true that if you have a child you want it to be perfect, and then you get a diagnosis of autism, or fragile X, or whatever and it kind of blows you away and you sort of mourn the child that you now don't have, but you have to learn to see them in a different light and accept them for who they are and it really isn't a problem, it is only a problem if you make it a problem. That was the most valuable thing that I took out of it. That and speaking to other parents. Yeah, those two things.

10. What did you find least valuable?

I don't know, I suppose stuff that they were talking about that didn't apply, but that's fine because there were varying degrees of need in the room. There were some grandparents there who were crying because they didn't understand what was what with their grandson, that was difficult. There are varying degrees there.

11. Have you learnt anything at EarlyBird that you think you would not have learnt at your child's nursery school?

Quite a lot really. Um, well I think that they had done some EarlyBird stuff, and actually came for one or two sessions and she had done most of it before. I think the strategies that I got from EarlyBird were unique and I definitely got more from earlybird because it was geared that way.

12. Are there alternative interventions that you would have preferred for your child?

Um, no, I suppose not, everything was pretty much ok. The thing about over the moon was that they had pretty good SEN contact which they told me about. We also got some extra funding to pay for school which they put me in the loop about too.

13. Over the past 6 months how do you think your child has changed?

The most significant really is his speech. He has really come along there, um, we kind of down play it for the statement. The minute they see that there is a vast improvement that might take it and give it to someone else. I think that he has matured a bit too, not a lot, but he won't be left behind. It has been more than 6 months, but he is wanting to do stuff himself, like pour his milk and juice. He wants to be more independent definitely. Behaviour wise he is more defiant. He is more capable of knowing consequences too. He still can't hold himself back and has to go rushing in. He doesn't have that self control to hold himself back and plan a task. He jumps in and does it.

14. What do you think that these changes are a result of?

Um, well growing up, he is also in a school environment with an LSA a lot and he also has some OT. A lot is due to the input that he is being given in the school environment. We do stuff here too on a daily basis, but sometimes you forget! I think it is due to a lot of that input and having a statement. I also think that me doing EarlyBird gave me a better understanding of things and how to deal with things. Yeah, I think it mostly due to school and him having a lot more structure.

15. How would people who know you well describe your character?

Oh gosh, I don't know, um, favourably I suppose!

16. How would you describe yourself as a parent?

-calm, relaxed, anxious

I think I am doing what every parent does, the best they can. I don't always deal with things the best way often you are tired or fed up but all in all I think I have done a pretty good job.

17. Is this different from how you would have described yourself 6 months ago?

Not really, I think I try to be consistent!

18. How do you think having a child with special needs has impacted on family life?

- positive
- negative
- siblings

Um, well we had to move that is big, it did impact you go through the whole denial thing and have fights with the family and then the diagnosis comes in and you accept it. It has impacted a lot. I think initially you are so shocked and everything is negative, something they can't do, everything is bad, you see them as not normal, you separate them from the normal and I think we still do that we know that he is not completely normal but that's fine he goes to a mainstream school, he has friends. It has made us more understanding of things. My sister is disabled, I grew up with it but I never really thought about it at all until I had children that were special needs now special needs are big on the agenda whereas before I never even considered it, never thought about what governments did for special needs. It has impacted, but in a good way. I was talking to some parents and they say that they have no life sometimes, but their children are different and you have to accept them for who they are. It makes you more tolerant and helps normal kids to be more tolerant. We didn't have that growing up, we didn't really see children with special needs, and they just weren't there. They were almost like Victorians and locked them away. My kids have got Down syndrome kids in their classes and it makes kids more tolerant.

19. Do you view your child differently now than you did 6 months ago?

I see the improvement so in that way I view him differently. He is coming into himself now. He is five now, but still my baby! Yeah, I mean seeing the changes are good but I don't see him different in any other way. His behaviour is sometimes difficult but I accept it as part of his difficulties and accept that certain things are part of the parcel; I don't see him as anything negative.

20. Where do you see your child in 2 years?

Well um, he will be at juniper hill but I hope that his speech will be so much better that he can carry on conversations with his mates, I hope that he can speak on the phone, in general I want him to improve and get better and hopefully in the new year he will have a SALT. I have been writing letter to them and threatened tribunal in July and have said that time and again so somebody called me after that and write a letter.

21. Have you had any contact with autism lobby groups since your child was diagnosed?

- if yes, who, what support did they provide, what was the reason for contacting them?

No, the only advocacy group that I have come across is parent partnership which has been great, they are going to get a website going to help parents, also give advice on statements and legal advocacy. They are planning some meetings with counsellors as money is not allocated and it is difficult for parents. That is the only advocacy group I have come across. Also the national autistic society. The fragile x society is great, it was started by parents of fragile x kids, it is great and brilliant to talk to other parents. They have lots of

stuff on their website. I spoke to a lady there who was the one who had the idea about the tribunal. You call them up and don't have to explain anything to them. I contacted them initially to find out about the issues and then managed to make contact that way. They are a great society, parent partnership too. They rally for all parents. They are good yeah, great.

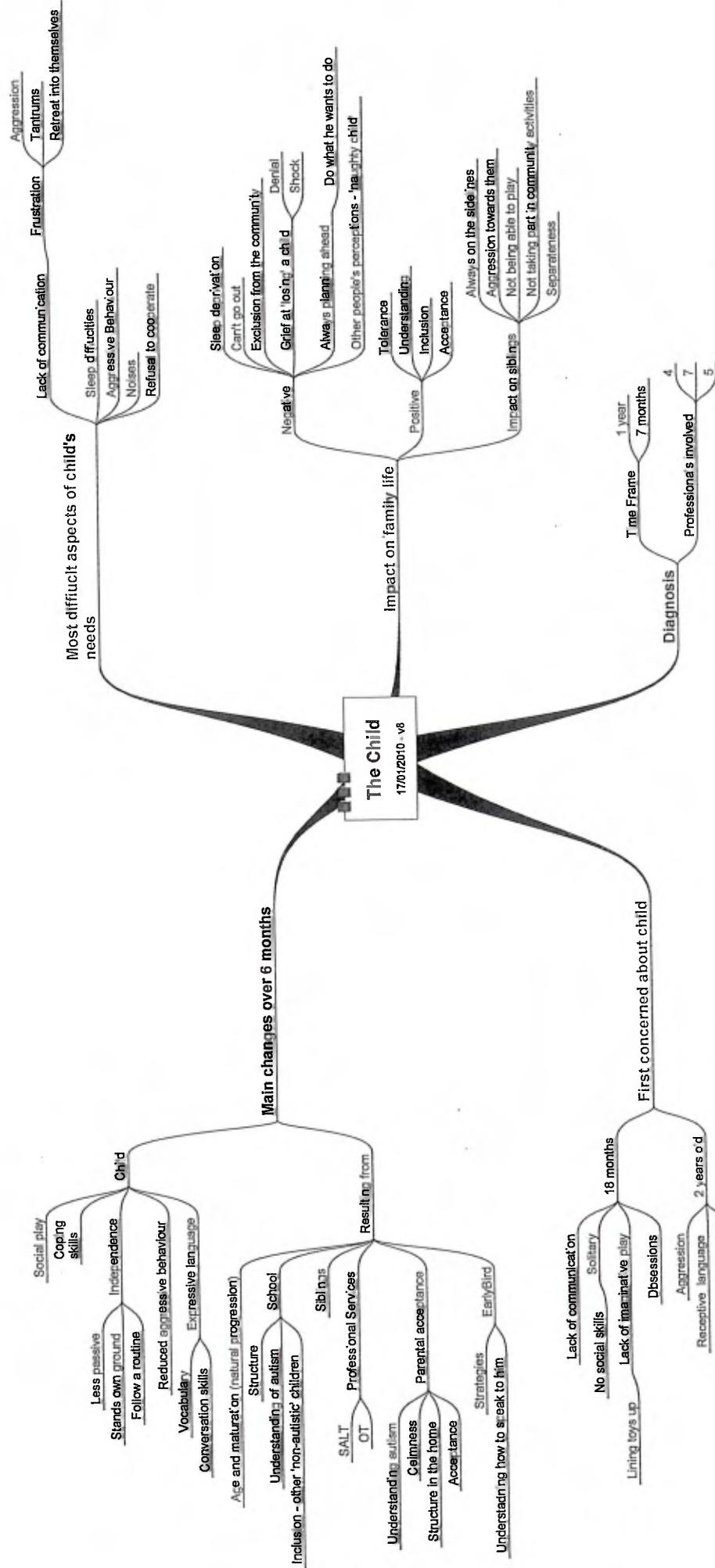
Other

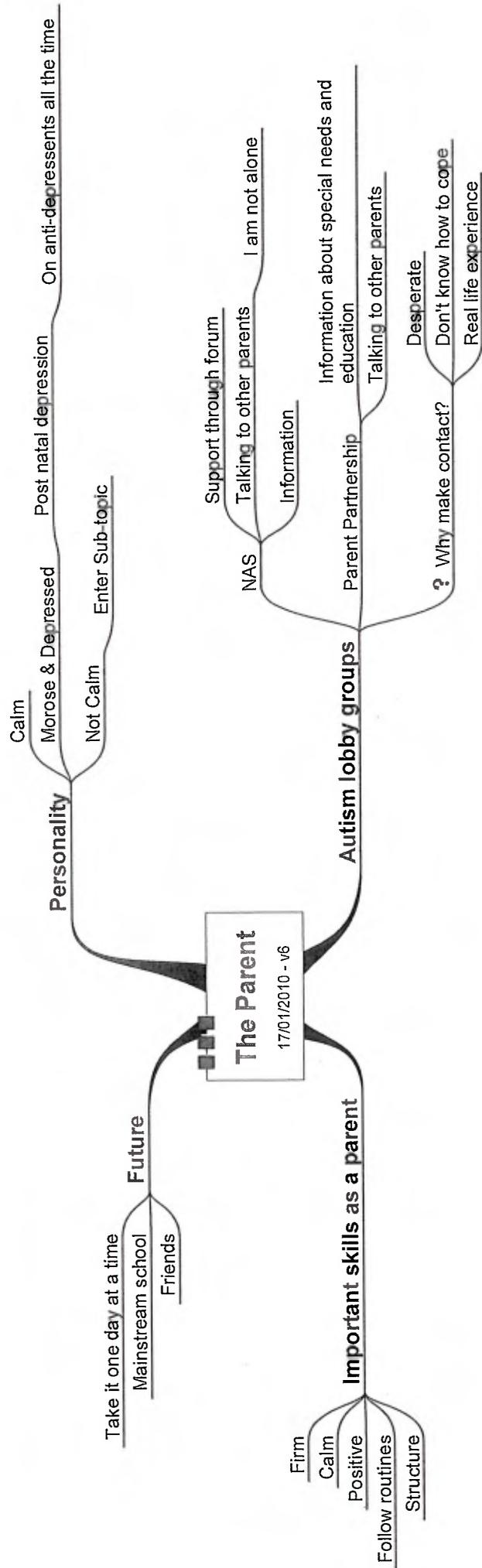
The whole thing is that they don't know how to speak to parents perhaps they don't have any special needs children. It is their job to speak to parents though. There is no clear list of who you can speak to. People get made redundant, they leave and you don't know. The reports that the therapists were doing were pretty comprehensive and thorough, but the statements are a bit unclear about what it is that they need. They say that they need access to his and that but it is all kind of vague. Parents feel that they are in the dark, they don't know that there are things they can do like request rewording. Things like which section of the statement it needs to be in for it to be legal. Parents don't know where to look and depending what the needs of the child are depends on what you need.

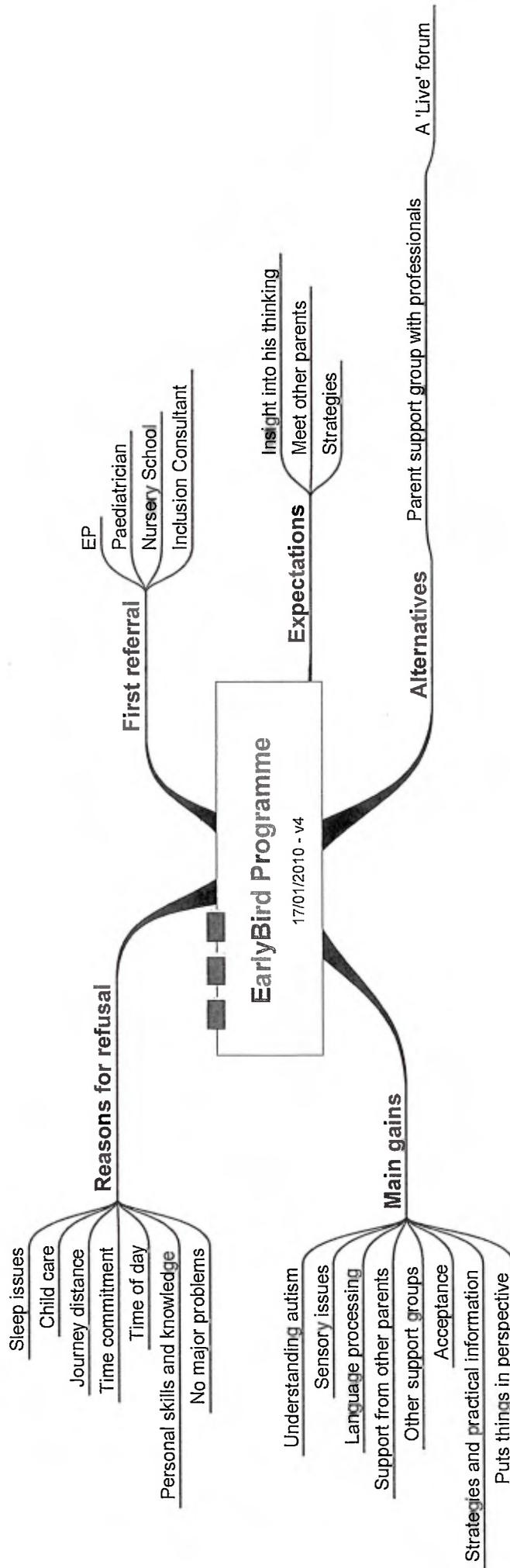
Stuff that is in the statement they don't get there is a huge waiting list and there are a shortage of therapists and so on so they just don't get it. But that is not our problem, they should sort it out. People leave and we don't know. What happens to their in tray when they leave? I had written to someone who left and never heard anything back. It is frustrating you don't get updates. We deserve to know where our money goes. Things like parent partnership are good though as you speak to other parents and don't feel like you are alone. We also come up with ideas together and share ideas. It makes you feel like you have more power and you are not alone otherwise I think you feel that you are banging your head about the wall. I only found out about parent partnership through EarlyBird. I went to the meeting after that and it is really good to be involved with it. The more of us that get together the better.

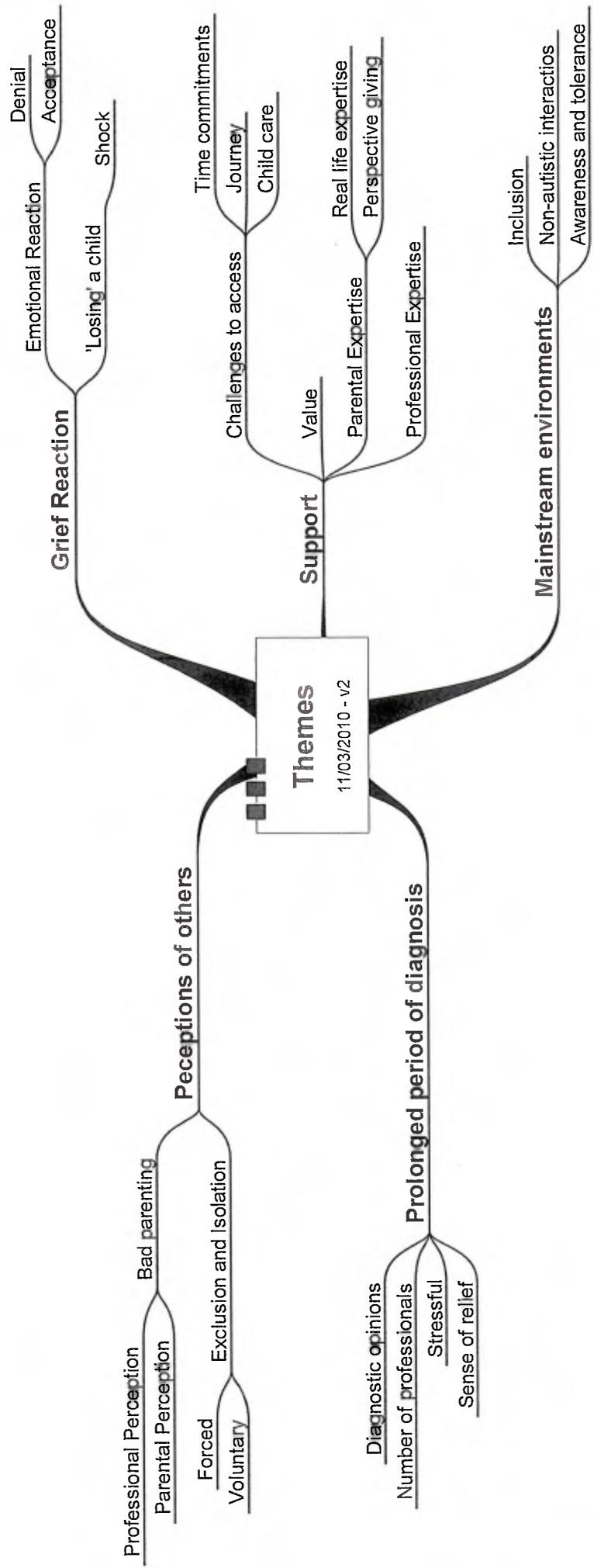
APPENDIX 9

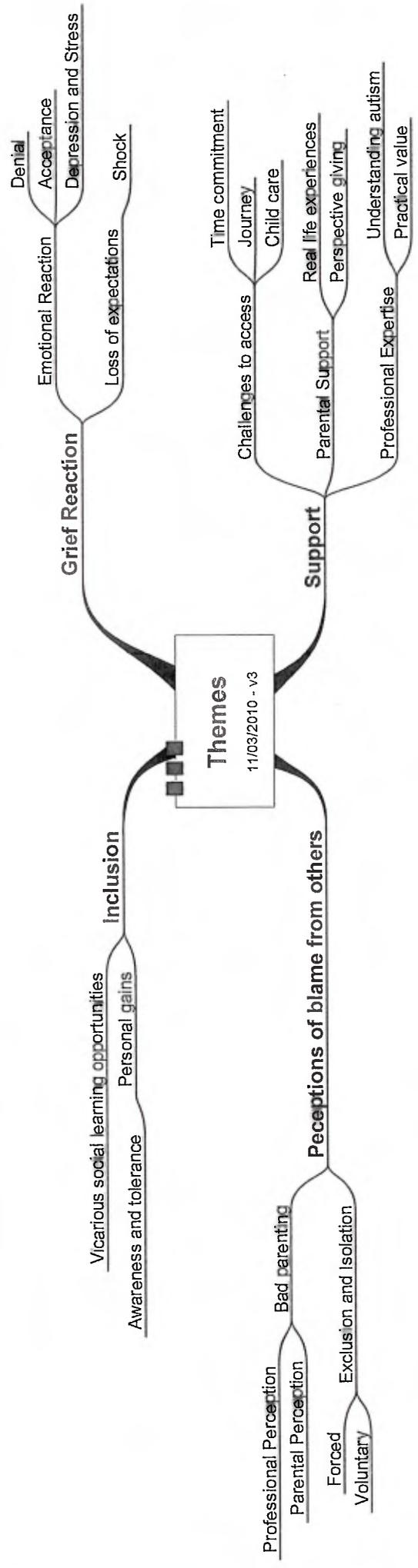
THEMATIC ANALYSIS







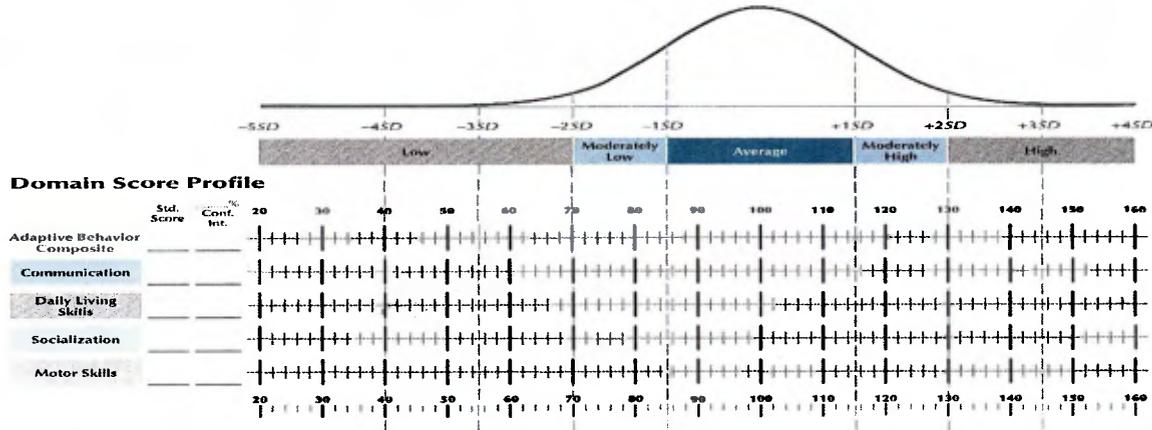




APPENDIX 10

INDIVIDUAL PARTICIPANTS' RESULTS

VINELAND-II SCORE PROFILE



JACK

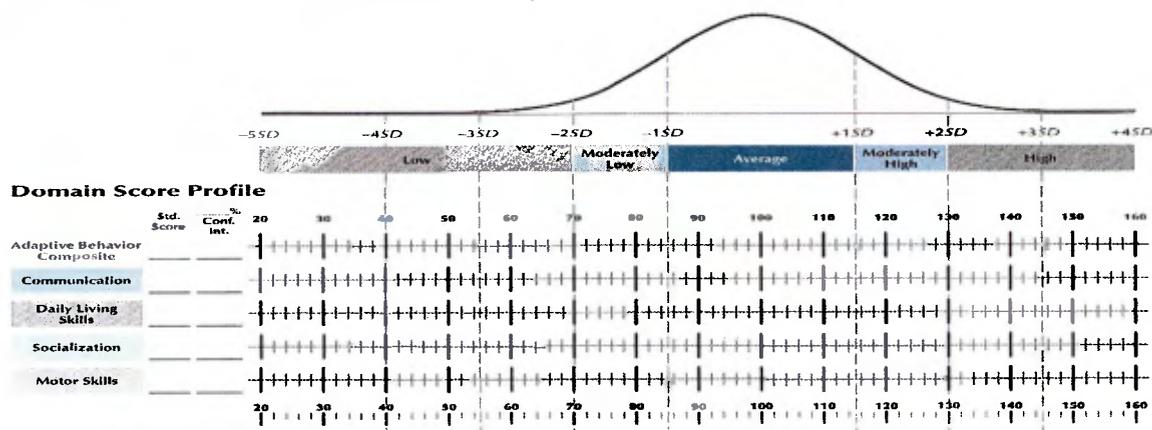
CHRONOLOGICAL AGE 53 61 8

VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT (Months)		DIFF
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
Communication					67	76	6	5			
Receptive	20	32	9	14					19	55	36
EXTIME 1ssive	50	53	9	9					27	29	2
Written	2	4	11	10					29	37	8
DAILY LIVING SKILLS					75	79	5	8			
Personal	32	35	9	8					30	32	2
Domestic	6	10	12	13					30	47	17
Community	12	11	12	14					38	37	-1
SOCIALISATION					66	74	1	4			
Interpersonal Relationships	32	32	10	9					22	22	0
Play and Leisure Time	8	25	7	10					9	31	22
Coping Skills	10	19	10	12					25	40	15
MOTOR SKILLS					72	72	3	3			
Gross	67	68	11	11					37	38	1
Fine	30	36	10	10					32	38	6
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2					
	67	72	1	3	Low	M.Low					

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	4	2	4	3	2	1
Communication	17	3	9	4	9	2
Social Interaction	7	5	4	3	1	1
Autism Index			72	57	3	<1

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT		GCA	
LOWER LEVEL CORE	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Block Building	57	57	30	20	2	1	<2.6	<2.6	Sscore	61 66
Verbal ComTIME 1hension	77	88	31	32	3	4	<2.6	<2.6	%ILE	0.5 1
Picture Similarities	10	53	20	36	1	8	<2.6	<2.6		
Naming Vocabulary	63	83	33	37	4	10	<2.6	<2.6		

VINELAND-II SCORE PROFILE



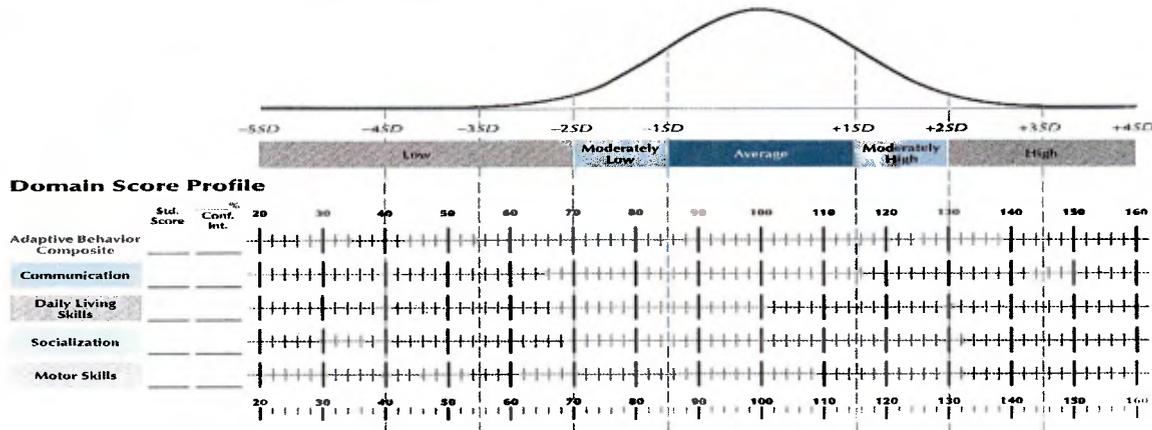
CHRISTOPHER CHRONOLOGICAL AGE 47 55 8

VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
COMMUNICATION					85	100	16	50			
Receptive	20	27	9	12					19	34	15
Expressive	85	92	16	17					53	66	13
Written	4	11	13	16					37	58	21
DAILY LIVING SKILLS					100	113	50	81			
Personal	53	63	15	18					48	70	22
Domestic	11	19	15	18					54	84	30
Community	16	22	15	16					46	58	12
SOCIALISATION					72	75	3	5			
Interpersonal Relationships	37	36	11	11					29	28	-1
Play and Leisure Time	12	19	8	9					25	34	9
Coping Skills	12	16	11	12					27	34	7
MOTOR SKILLS					91	100	27	50			
Gross	69	72	13	13					41	46	5
Fine	42	57	14	17					46	70	24
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2					
	84	96	14	39	M. Low	Av					

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	18	14	9	8	37	29
Communication	16	8	9	6	37	9
Social Interaction	15	23	7	10	16	50
Autism Index			89	87	23	19

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT		GCA	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Block Building	57	77	33	34	4	5	<2.6	2.10	98	103
Verbal Comprehension	102	113	47	48	38	42	3.4	4.4	45	58
Picture Similarities	59	57	46	40	34	16	3.1	2.10		
Naming Vocabulary	107	141	67	80	96	99	5.7	8+		

VINELAND-II SCORE PROFILE



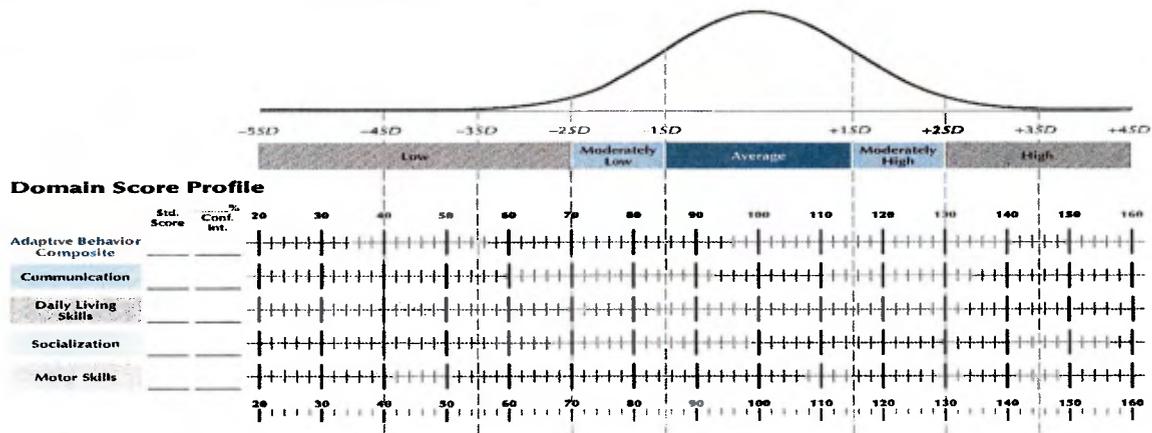
RORY CHRONOLOGICAL AGE 34 40 6

VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
COMMUNICATION					61	65	<1	1			
Receptive	8	11	7	6					9	12	3
Expressive	15	23	8	8					9	16	7
Written	0	4	/	14					0	37	37
DAILY LIVING SKILLS					73	64	4	1			
Personal	13	13	8	7					15	15	0
Domestic	4	4	12	11					22	22	0
Community	3	4	11	10					11	18	7
SOCIALISATION					76	77	5	6			
Interpersonal Relationships	21	26	9	9					7	15	8
Play and Leisure Time	11	24	10	12					12	30	18
Coping Skills	12	10	13	12					27	25	-2
MOTOR SKILLS					77	134	6	99			
Gross	56	77	13	20					27	65	38
Fine	19	60	9	20					19	65	37
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2					
	68	82	2	12	Low	M.Low					

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	29	29	13	13	84	84
Communication	36	34	16	16	98	98
Social Interaction	36	31	15	14	93	91
Autism Index			130	128	98	98

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT		GCA		
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
Block Building	32	57	34	36	5	8	<2.6	<2.6	Sscore	60	77
Verbal ComTIME 1hension	10	57	20	28	1	1	<2.6	<2.6	%ILE	0.4	6
Picture Similarities	17	48	27	42	1	21	<2.6	<2.6			
Naming Vocabulary	37	66	31	42	3	21	<2.6	<2.6			

VINELAND-II SCORE PROFILE

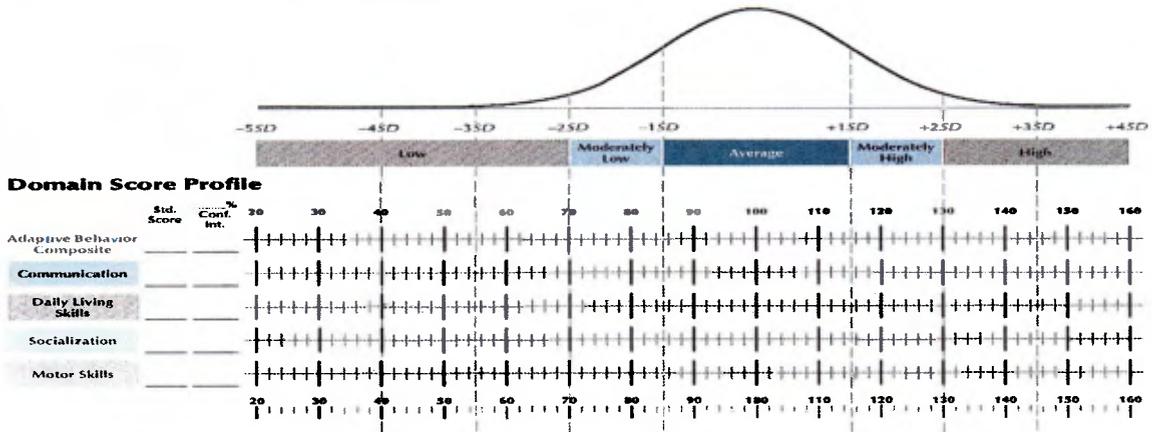


OSCAR					CHRONOLOGICAL AGE				52	59	7
VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
Communication					47	65	<1	1			
Receptive	7	7	4	7					8	14	6
Expressive	11	8	4	8					9	25	16
Written	4	13	12	13					37	51	14
DAILY LIVING SKILLS					62	58	1	<1			
Personal	17	28	7	8					19	27	8
Domestic	3	2	10	9					18	14	-4
Community	8	6	10	8					29	26	-3
SOCIALISATION					70	61	2	<1			
Interpersonal Relationships	16	20	6	7					5	7	2
Play and Leisure Time	4	6	6	6					4	7	3
Coping Skills	2	12	7	11					4	27	23
MOTOR SKILLS					59	67	<1	1			
Gross	50	58	9	10					22	28	6
Fine	22	30	7	9					23	32	9
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2					
	57	60	<1	<1	Low	Low					

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	21	28	10	13	50	84
Communication	47	34	19	16	99	98
Social Interaction	27	25	12	11	75	63
Autism Index			124	122	95	93

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT		GCA		
LOWER LEVEL CORE	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
Block Building	REF		REF		REF		REF		Sscore	n/a	n/a
Verbal ComTIME 1hension	REF		REF		REF		REF		%ILE	n/a	n/a
Picture Similarities	REF		REF		REF		REF				
Naming Vocabulary	REF		REF		REF		REF				

VINELAND-II SCORE PROFILE



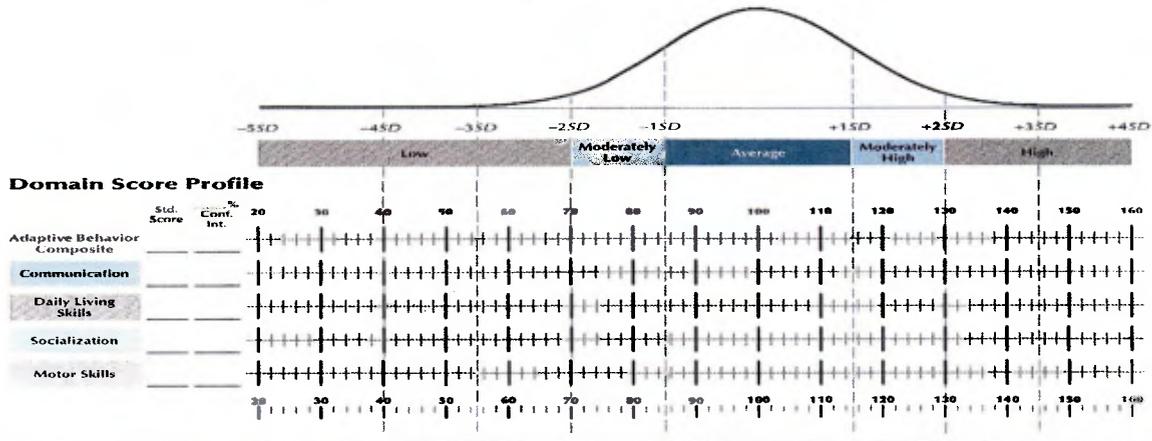
WILLIAM CHRONOLOGICAL AGE 42 49 7

VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF
SUBDOMAIN/DOMAIN	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
Communication					47	42	<1	<1			
Receptive	6	6	3	3					6	6	0
Expressive	12	16	6	5					8	9	1
Written	1	0	11	9					25	22	-3
DAILY LIVING SKILLS					73	64	4	1			
Personal	30	28	11	9					28	27	-1
Domestic	1	2	10	9					10	14	4
Community	6	6	11	10					31	26	-5
SOCIALISATION					66	61	1	<1			
Interpersonal Relationships	19	14	7	6					6	4	-2
Play and Leisure Time	8	6	8	7					9	7	-2
Coping Skills	11	12	12	11					26	27	1
MOTOR SKILLS					72	78	3	7			
Gross	50	63	10	12					22	33	11
Fine	26	30	11	11					27	32	5
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2					
	62	61	1	<1	Low	Low					

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	24	33	11	15	63	95
Communication	NV	9	NV	6	NV	9
Social Interaction	24	29	10	12	50	75
Autism Index			133	106	99	65

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT		GCA	
LOWER LEVEL CORE	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Block Building	10	10	23	20	1	1	<2.6	<2.6	Sscore	59 62
Verbal ComTIME 1hension	10	10	20	20	1	1	<2.6	<2.6	%ILE	0.3 0.6
Picture Similarities	36	74	34	56	5	73	<2.6	4.7	NV Composite	
Naming Vocabulary*	51		32		4		<2.6		Sscore	65 81
Naming Vocabulary	10	26	20	20	1	1	<2.6	<2.6	%ILE	1 10

VINELAND-II SCORE PROFILE



MATTHEW CHRONOLOGICAL AGE 40 47 7

VINELAND-II	RAW SCORE		V-SCALE SCORE		DOMAIN STANDARD SCORE		% ILE RANK		AGE EQUIVALENT		DIFF
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
COMMUNICATION					104	108	61	70			
Receptive	23	26	11	12					22	29	7
Expressive	66	73	13	14					34	39	5
Written	26	26	24	24					83	83	0
DAILY LIVING SKILLS					87	83	19	13			
Personal	30	33	11	10					28	30	2
Domestic	4	6	11	13					22	30	8
Community	19	15	17	14					53	42	-10
SOCIALISATION					74	77	4	6			
Interpersonal Relationships	17	26	7	9					6	15	9
Play and Leisure Time	10	17	9	10					11	18	7
Coping Skills	20	17	15	14					41	35	6
MOTOR SKILLS					88	81	21	10			
Gross	48	52	10	10					21	24	3
Fine	41	39	16	14					42	45	3
ADAPTIVE BEHAVIOUR COMPOSITE	STANDARD SCORE		% ILE RANK		ADAPTIVE LEVEL						
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2					
	87	84	19	14	AV	M.Low					

GARS	Raw Score		Standard Score		%ile	
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2
Stereotyped Behaviour	13	4	7	4	16	2
Communication	24	12	12	7	75	16
Social Interaction	20	12	9	6	37	9
Autism Index			96	72	39	3

EARLY YEARS BAS-II	ABILITY SCORE		T-SCORE		% ILE		AGE EQUIVALENT		GCA		
	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	TIME 1	TIME 2	
Block Building	REF	68	REF	36	REF	8	REF	<2.6	Sscore	n/a	108
Verbal Comprehension	REF	102	REF	47	REF	38	REF	3.4	%ILE	n/a	70
Picture Similarities	REF	79	REF	63	REF	90	REF	5.4			
Naming Vocabulary	REF	107	REF	67	REF	96	REF	5.7			

APPENDIX 11

INFORMAL BEHAVIOURAL OBSERVATION SHEET

Informal Behavioural Observation

Name of Child: _____ Research Name: _____

Date of Observation: _____ Pre/Post

Start time: _____

Parent Present: Yes/No

End time: _____

Place of observation: _____

Social Interaction (peers and staff):

Communication:

Spoken Language/Expressive Language/non-verbal communication:

Understanding of language:

Play:

Independence:

Attention/concentration:

Overall Behaviour:

Other:

Informal Behavioural Observation

Name of Child: M Research Name: Matthew
 Date of Observation: 09.04.09 (Pre/Post)
 Start time: 9.30 am Parent Present: Yes/No
 End time: 10.15 am Place of observation: School

Social Interaction (peers and staff):

No interaction with staff or peers. Does not try & get attention of staff. Talking to himself. Not interested in sharing activity or interest with others.

Communication:

Spoken Language/Expressive Language/non-verbal communication:

Talking to self lots. Staff asks que - Max repeats que. When asked what doing - repeats 'what you doing Max'. Talking about solar system whilst drawing. No exp. to other children. Lots repetition. Echoing

Understanding of language:

Does not respond to requests - repeats what said - staff had to lead him out - no response to verbal instructions. Can understand and respond to some familiar routines in context. Needs to be motivated though.

Play:

Stands or idles. Watching other ch. Playing alone - not really play - staff rep. that observed with solar system. Drawing - solar system. Knows lots about it! No play with others. Does not show interest in what others doing.

Independence:

Plays alone. Not int. w/ staff or children. Talking fine - no ripples. Not really int. w/ staff or ch. Staff said he will ask for drink or food though.

Attention/concentration:

Maintains att for long time when motivated. Did not see him do any other activities. Staff tried to get him to join in but he went back to what doing.

Overall Behaviour:

Upset by me being there - saying 'Goody go' Calmed quickly though & went back to activity
 Other: Did not respond to me at all once calmed.