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CITY UNIVERSITY LONDON

A Cross-national Study of Childhood Autism

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Thesis submitted for the degree of Doctor of Philosophy

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September 2015

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ACKNOWLEDGEMENTS

Firstly, I wish to thank my supervisors, Dr. Nicola Botting and Dr. Julia Jones for their continuous guidance, support and helpful suggestions and for challenging me during the past few years. I could not have done this without them!

A heartfelt thanks to the therapists who agreed to refer families from their caseloads and my deepest gratitude to the families that participated in the study. Thank you for devoting your time! Without their contribution this thesis would not have been completed.

I also want to thank my family, especially my parents, for their relentless support and encouragement throughout this journey. Thank you for believing in me when I needed it the most and for always being there for me. I am also grateful for the encouragement of my friends and for being patient and understanding during the course of this project.

Finally, I want to thank my husband. This study would have not been possible without his support, encouragement and love. I truly thank him for sticking by my side and having faith in me!

ABSTRACT

Autism is considered to be a chronic developmental disability that affects communication, relationships, emotional development and imagination (NAS, 2010). Prevalence rates for autism spectrum disorder (ASD) suggest that the rates have increased over time and recent research shows that 1 in 68 children are diagnosed with the disorder (Baio, 2014). These children's difficulties in the areas of communication, social skills and restricted/repetitive behaviours and interests lead to the need of therapeutic support (APA, 2013) and often it falls to parents to find an appropriate treatment for their child (Marcus et al, 2005). Among recommended services to these children are speech and language therapy, occupational therapy (Johnson and Myer, 2007) and psychotherapy (Alvarez et al, 1999). There are a number of intervention approaches for children with autism that have been developed, however none have been universally accepted as being the most effective (Farrell et al, 2005). As a result, parents often find it difficult to know which is the most appropriate approach for their child.

This study aims to explore the development of children with autism over time in the areas of social skill and communication, regardless of the kind of treatment (speech and language therapy, psychoanalytic/psychodynamic psychotherapy and occupational therapy) they are receiving and to investigate the association between therapy context and the patterns of developmental change. This thesis is designed as a cross-national study in order to examine the aspects of the disorder that differ in the UK and Greece along with the differences (if any) in the developmental patterns across countries. The significance of doing a cross-national study is to explore autism from a wider international perspective and to identify any differences and similarities across the two countries.

Twenty children with autism who had completed one of two differing types of treatment in the UK (psychotherapy, n=10 and speech and language therapy, n=10) were recruited to be monitored post-therapy twice over a two-year period. Twenty children with autism who had received one of two types of treatment in Greece (occupational therapy, n=10 and speech and language therapy, n=10) were also recruited to be monitored post-therapy twice over a two-year period.

The research found that all children changed significantly over time on all aspects of measurement. Furthermore, no significant differences were found in the children from the two different countries at the start of the study and they developed in a very similar way as well. The results suggested though that based on the ADOS-Social ($p=0.008$) and ADOS-Imagination ($p=0.008$) children in the UK improve faster in the areas of social skill, imagination and the CDI-no of words understood and produced ($p=0.015$) showed an increase in their ability to understand and say words compared to the children in Greece. However, the CDI-no of words understood ($p=0.027$) showed that the children in Greece improved faster in the area of comprehension. The children who received SLT are also mainly developing in a very similar way across the two countries. Most measures showed change over time, except for the SCQ ($p=0.081$), ADOS-Ster ($p=0.050$) and CDI-U ($p=0.141|$). Also, only the ADOS-Social ($p=0.021$) and the Social Communication Questionnaire ($p=0.021$) showed a significant interaction effect. Thus, the SLT group from the UK seems to improve faster in the area of social skills compared to the SLT group from Greece.

Additionally, in regards to the effect of the therapy context on the developmental pattern of children with autism, there were no differences across intervention contexts at the beginning and there were mainly non-significant interactions in the rate of change across the differing types of intervention. The

findings suggested that all measures showed change over time. Only the SCQ ($p=0.041$) and the ADOS-imagination ($p=0.033$) showed a significant interaction effect before adjusting for age. Therefore, the SLT group in the UK seems to improve faster in the social communication area and the Psychotherapy group in the UK improved faster in the area of imagination.

Conclusively, the SLT groups showed more change on language and communication measures, whilst the psychotherapy and occupational therapy groups saw changes in other areas of autistic symptomatology not achieved in the SLT groups, such as imagination and stereotypical behaviour.

In summary, the current study helps parents gain better insight in different therapy choices and raises awareness of other types of therapy that are available in terms of intervention. The findings of this study can help professionals who work with children with autism further their understanding of the disorder and how it manifests through time in order to provide appropriate services based on each child's needs. Additionally, the cross-national approach was intended to give some suggestions about the manifestation of autism across countries and about the way childhood autism is treated in each country. In regards to the more specific changes that the analysis revealed, they seem to fit well with the intervention targets of each type of therapy. Thus, the analysis suggested that certain characteristics tend to be associated with specific treatment types, which leads us to believe that sometimes the most effective course of treatment is a combination of therapies depending on the individual needs of each family. Finally, the results of this study offer original findings with respect to the outcomes of psychodynamic/psychoanalytic psychotherapy for children with autism since there is a lack of rigorous research in this field.

ABBREVIATIONS

AAC	Alternative Augmentative Communication
ABA	Applied Behaviour Analysis
ALM	Aided Language Modeling
APA	American Psychiatric Association's
ASD	Autism Spectrum Disorder
BRIAAC	Behaviour Rating Instrument for Autistic & Atypical Children
CA	Chronological Age
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Groups
CDC	Child Development Centres
CELF	Clinical Evaluation of Language Fundamentals
CELF-FS	Clinical Evaluation of Language Fundamentals -Formulating Sentences
CELF-CFD	Clinical Evaluation of Language Fundamentals – Concepts and Following Directions
CSS	Calibrated Severity Scores
DBC	Developmental Behaviour Checklist
DI	Direct Instruction
DIR	Developmental, Individual Difference, Relationship-based
DoH	Department of Health
DQ	Developmental Intelligence Quotient
DSM	Diagnostic and Statistical Manual of Mental Disorders
DTT	Discrete Trial Teaching

EOPYY	National Organization for Healthcare Provision
ESY	National Health System of Greece
FCT	Functional communication training
FNP	Family Nurse Partnership
GDP	Gross Domestic Product
GP	General Practitioner
HETA	Hopes and Expectations for Treatment Approach
HCAM	Hampstead Child Adaptation Measure
HFA	High Functioning Autism
ICD	International Classification for Diseases
IACC	Interagency Autism Coordinating Committee
ICD	International Classification of Diseases
IEP	Individual Education Plan
IPCA	Inventory of Potential Communicative Acts
KDAY	Diagnosis Evaluation and Support Centres (Greece)
KEDDY	Differential Diagnosis, Diagnosis and Support for Special Educational Needs
MOU	Memorandum of Understanding
NAS	National Autistic Society
NBLI	Narrative Based Language Intervention
NLP	Natural Language Paradigm
NHS	National Health Service
NGO	Non-governmental organizations
NICE	National Institute for Health and Care Excellence
OO	Optical Outcome
OT	Occupational therapy

PACT	parent-mediated communication-focused treatment
PCP	Person Centred Plan
PROMPT	Prompts for Restructuring Oral Muscular Phonetic Targets
PPP	Public-Private Partnerships
PDD-NOS	Pervasive Developmental Disorder-Not otherwise specified
PCT	Primary Care Trusts
PRT	Pivotal Response Training
PECS	Picture Exchange Communication System
RJA	Responsiveness to joint attention
RPMT	Responsive Education and Prelinguistic Milieu Teaching
RRB	Restricted and Repetitive Behaviours
REEL	Receptive-Expressive Emergent Language Scale
RIT	Reciprocal Imitation Training
SGD	Speech Generating Device
SCQ	Social Communication Questionnaire
SENS	Special Education Needs Statement
SEN	Special Educational Needs
SLCN	Speech, Language and Communication Needs
SLT	Speech AND Language Therapy
SBRS	Social Behaviour Rating Scale
SIT	Sensory Integration Therapy
SENCO	Special Educational Needs Co-ordinator
TEACCH	Treatment and Education of Autistic and Related Communication Handicapped Children
WHO	World Health Organisation

Chapter 1 Introduction

1.1 An introduction to the thesis

This thesis presents a cross-national, longitudinal study focusing on the progress of children with autism over time and on different approaches of treating childhood autism in the UK and Greece. The study aims to provide information about the progress of children with autism in the areas of social skill and communication after therapy, regardless of the kind of treatment (speech and language therapy, psychotherapy and occupational therapy) they are receiving and to explore the associations between the therapy context and the children's developmental change. A further aim is to compare data on the progress made by each child over the course of the research in the two different countries (the UK and Greece).

1.2 An introduction to autism

Autism is a neurodevelopmental disorder that affects the forming of relationships, communication and language skills as well as emotional development and imagination. According to the National Autistic Society (2010) autism is a lifelong developmental disability. It is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder (ASD). The word 'spectrum' is used because there is so much deviation in the types and level of severity of each symptom that it brings to mind a 'spectrum' of symptoms and level of function. It is a highly complex disorder that affects social communication, social interaction and imagination (triad of impairments) in individuals. The presented symptoms are known to change with development and can vary depending on the cognitive impairment associated with the disorder (Filipeck et al., 1999) but consist specifically of difficulties in acquiring and developing social, language, cognitive and motor skills.

Autism was once thought of as a rare condition (Kanner, 1943; DSM-III-R, 1987). According to the most recent 'Centres for Disease Control and Prevention' report (Baio, 2014) the prevalence of autism (for the period of 2010) has risen to 1 in every 68 births in the United States and almost 1 in 54 boys. Research (Baird et al, 2006) suggests that one in 100 people in the UK have autism and it is noted by some researchers (Gillberg & Wing, 1999; Webb et al, 1997; Wing, 1997) that there is an increase in children being diagnosed with autism. However, there is an argument on whether this is actually true or if it is caused by the changes in the diagnostic criteria and the increased awareness. Baron-Cohen et al (2009) carried out a diagnosis survey of autism-spectrum cases using the Special Educational Needs (SEN) register in order to estimate the prevalence of autism in the UK. Based on the results the prevalence was estimated to be 157 per 10000 for children aged 5-9 years old. Research also shows that people with autism have many similarities, no matter what their culture is, or where they come from (Gonela, 2006). It should be taken into account though that investigating the prevalence and nature of autism across countries has received limited attention and this focus will form one strand of the thesis.

Hoppes & Harris (1990) note that to a parent/caregiver the autistic child's deficit in social responsiveness may be the most disturbing feature of the disorder. This reduced capacity for attachment, identification and empathy is considered to be one of the major disabilities of the child with autism. While most people with autism share the three main areas of difficulty mentioned earlier, their condition will affect them in very different ways. Some individuals are able to live independently whereas others will require a lifetime of specialist support (National Autistic Society, 2010).

1.2.1 Definitions of autism

The way autism has been diagnosed has changed over time and as commented by Acquarone (2007), each decade has brought its own contribution to understanding the condition. Kanner (1943), an Austrian psychiatrist and physician, was the first to define autism as an affective disorder caused by deficient parental interaction.

Autism was defined until recently as a Pervasive Developmental Disorder (PDD) in the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994) and the World Health Organisation's (WHO) International Classification of Diseases (ICD-10, 1992). Pervasive developmental disorder (PDD) was an umbrella-like term, which included a group of developmental disorders. That group included autism, PDD-NOS (pervasive developmental disorder not otherwise specified), Asperger's syndrome, Rett's Syndrome and childhood disintegrative disorder.

When the DSM 5th edition (DSM-5, APA, 2013) was introduced in May 2013 the ASD diagnosis stopped being used as an umbrella term and the previous sub-classifications were removed. The current diagnostic criteria for Autism Spectrum Disorder (ASD) include deficits in social communication and interactions, and restricted interests or repetitive behaviours. If no restricted interests or repetitive behaviours are presented then the individual is diagnosed with social communication disorder.

Autism Spectrum Disorder is considered to be quite heterogeneous with respect to the presentation and intensity of its symptoms and the DSM-5 includes levels of severity based on the support that the individual needs (Level 1-requiring support, Level 2- requiring substantial support and Level 3-requiring very substantial support). Also, the DSM-5 states that a diagnosis is justified when the symptoms are causing

significant impairment in the individual's social, occupational, educational or other areas of functioning and that symptoms must be present in early development (APA, 2013). The revision of the diagnoses and criteria for an ASD are supposed to make the diagnoses more consistent among clinicians. Nonetheless, the changes made in DSM-5 have been met with controversy in the mental health field. As stated by Lord and Bishop (2015, p.64) "significant changes to established systems are never met without controversy". The main concern has to do with individuals with milder autism symptoms or the ones previously diagnosed with Asperger's, who might now be excluded (McPartland et al, 2012). As it is commented by Wakefield (2013), some people might have welcomed this adjustment but there is a general concern that these individuals might miss out on special education support since they no longer fulfil the diagnostic criteria for an autism spectrum disorder.

1.2.2 Background to autism

Different areas of development may be affected by the autism spectrum disorder. In the area of social skills some individuals with ASD might find it difficult to develop appropriate peer relationships, they might show limited pleasure in shared interactions and they might have difficulties expressing themselves non-verbally (APA, 2013). With respect to communication deficits in ASD there are often language delays, lack of gestures, difficulties with reciprocal conversation, stereotyped or idiosyncratic language and impairments in all aspects of play. Furthermore, restricted interests or repetitive behaviours include obsessions or intense interests and routines and stereotyped or repetitive mannerisms, like hand flapping or finger-flicking (APA, 2013). Eminent variability exists in the area of language abilities since some individuals with autism might be verbally fluent but 30-50% of children with ASD are

reported to have significant impairments in their language skills (Howlin et al, 2004). Also, research shows that children with ASD face notable difficulties in several types of play, e.g. deficits in symbolic play development (Ungerer & Sigman, 1981).

Despite more than 50 years of research, experts still debate about the causes of autism (Baron-Cohen 2001; Buxbaum, Silverman & Smith, 2005) and try to determine the most appropriate tools to detect autism as early as possible. Debates about emotional or organic origins have influenced different types of therapy and treatment. Many researchers suggest that autism may be caused by genetic predisposition, brain insult, or brain disease (Buxbaum et al., 2004; DSM-IV-TR, 2000; Frith et al, 1991; Peeters & Gillberg, 1999; Lathe, 2006; Wing & Potter, 2002). Medical researchers have found that the main cause of autism could be biological or neurological differences in the brain. Significant differences in the cerebellum and other abnormalities in the brain have been shown in MRI and PET scans (George et al, 1992; Gillberg et al, 1993). The National Institute of Health's Interagency Autism Coordinating Committee (IACC) publishes reports that suggest genetic causes (Ozonoff et al, 2011; Van Meter et al, 2010). The IACC suggests that the fact that ASD symptoms and developmental trajectories vary within the disorder affects research and priorities.

Baron-Cohen et al (1992) conducted a study in Great Britain and Sweden which suggests that we can detect autism as early as 18 months, taking into account children's weaknesses in the social, communication and symbolic imagination level. Early intervention is necessary not only for the child but for the whole family as well. When children are treated when they are young better results can be seen in the communication area and the developmental progress (Notas and Mavropoulou, 2004).

Finally, the role of parents in the treatment of autism is important to consider.

According to Peeters (2000), early detection of autism leads to the selection of the appropriate treatment. However, there is a great number of different treatments on offer and it is very difficult for parents to choose. Therefore, it is important for parents of children with autism to obtain all the necessary information in order to gain a better understanding of their child's condition and select the appropriate treatment approaches. Autism is considered to be very costly for parents and according to Parish et al (2012) they spend more money on health care and therapies than parents of any other disability group. Many parents tend to turn to private clinics and services in order to increase the frequency and intensity of the treatment (Nickels, 2010). It is known to be difficult for parents to be fully prepared for a diagnosis of autism and it is likely and common to experience a range of emotions (Satkiewicz-Gayhardt et al, 2001). Individuals react in different ways and do not always know what is right or wrong for the family and the process of acquiring a diagnosis such as autism is often likened to bereavement (Dale, Jahoda, & Knott, 2006). Autism clearly has an impact on the whole family and is presented as a challenge to parents and caregivers.

There has been a growing public understanding of ASD in recent years but the increasing numbers of children that are diagnosed worldwide raise notable questions regarding the choice of therapy and the treatments that are the most effective for a family and children with autism. There is a growing demand to identify services that adequately meet the needs of these families and more research is required with respect to the types of treatment that are most helpful to increase children's social, communication and cognitive skills. The present thesis aims to give parents and caregivers greater insight into different therapy choices for the treatment of childhood autism.

1.3 A cross-national study of the UK and Greece

This study was conducted in the UK and Greece, more specifically in the cities of London and Thessaloniki. An important rationale for selecting these countries is that there are no other cross-national studies that have investigated the progress of children receiving different therapies for childhood autism in these two countries over time. Additionally, there is a large gap in the literature regarding the care of children with autism in Greece (Papageorgiou, 2005). Of additional relevance is that both London and Thessaloniki have a number of private centres that provide different types of treatment for childhood autism and thus could provide both the services and the participants for this study**.** In terms of the practicalities of conducting the research, it was beneficial that the researcher has professional experience and knowledge of services for childhood autism in these two countries, and in these particular cities, and speaks both Greek and English. Finally**,** little is known about the impact of cultural diversity on treatments used to support communication development in children with autism (Bridges, 2004) and this thesis addresses a further gap in this field.

With respect to the types of treatment included in this study; children that had speech and language therapy and psychodynamic psychotherapy were followed over time in the UK and children that had speech and language therapy and occupational therapy were followed over time in Greece.

Research suggests that speech and language therapy is one of the most commonly used treatments that children with ASD receive, both in Greece and the UK (Batten et al, 2006; Stampoltzis et al, 2012), which led to the investigation of this type of therapy in both countries. For example, Green et al (2006) explored the number and types of treatment used by parents for their children with autism and speech and language therapy was one of the most frequently used treatments.

The efficacy of psychodynamic/psychoanalytic treatment for autism has long been questioned (Alvarez 1996; Roser 1996). However, it is commonly used in the UK for children with autism (Reid et al, 2001; Alvarez and Reid, 1999). Therefore, it was considered important to explore further the use of psychotherapy for children with autism (Shelder, 2010). It is also deemed important to provide new information to the current evidence base regarding the progress of children with autism after receiving psychodynamic/psychoanalytic psychotherapy. Finally, the lack of rigorous research on the outcomes of a psychodynamically based approach to support children with autism led to the inclusion of the psychotherapeutic group in this study, in order to address this gap in the evidence base.

According to Green et al (2006) occupational therapy is among the most frequently requested services by parents of children with autism and other researchers (Mauer, 1999; Schaaf et al, 2013) indicate that the sensory integration approach is effective with children with autism. Of significance to this study, research by Stampoltzis et al (2012) highlighted that in Greece the majority of the children with autism had either private speech and language therapy or occupational therapy at least once per week. These reasons led to the inclusion of an occupational therapy group in the current study.

1.4 Treatment of Childhood Autism

There is a great variety of therapeutic approaches, which focus on accommodating or remediating different deficits related to autism. Siegel (1999:34) recommends taking a "kind of systematic eclecticism" to creating treatment programs for individuals. This means that various treatment models can be combined and be used throughout the process depending on the child's progressing needs, strengths and

weaknesses.

Following the diagnosis of autism and around the time that parents start to come to terms with their child's condition, they have to decide what kind of treatment plan they are going to follow. However, with so many different approaches and interventions available and due to the variability in the effectiveness of different treatments, it can be a difficult process for parents to decide which is the best path. A key focus of this thesis will be to explore the progress in children with autism undertaking three different types of treatment: Speech and Language Therapy, Psychodynamic Psychotherapy and Occupational Therapy. The literature reviewed in chapters 4, 5 and 6 concentrates on these treatments in depth. However a brief summary of each is given here. These are followed by an overview of other prominent therapies to provide a background context to the present study.

1.4.1 Speech and Language Therapy

It is well documented from previous research (Volkmar et al, 2009) that children with autism often have significant language development impairments. However these may be different to those seen in more specific types of language disorder (Williams, Botting, Boucher, 2008). The developmental course of language obtainment varies among children with autism. According to Volkmar et al (2004) approximately 25% of children with autism do not develop functional speech. Symptoms of ASD affecting communication may include deficits in expressive language and in non-verbal behaviours. Also, some children with autism exhibit symptoms of echolalia (repeating what they have heard like a script) or they might present with atypical-sounding speech characteristics (Bellon-Harn et al, 2007). Language is considered a vital part of social interaction and it is important to target the development of language skills of children

with autism in order to help them acquire the essential communication skills. Speech and Language Therapy (SLT) is one of the most frequently used services for children with ASD (Thomas et al, 2007). See Chapter Four for an in depth discussion of this type of intervention context.

1.4.2 Psychotherapeutic Approach

Children with autism often present difficulties when forming relationships; they exhibit poor play skills and eye contact and they might fixate on their special interests and objects (Bellon-harn et al, 2006). Psychodynamic Psychotherapy is an intervention that addresses social, emotional and behavioural problems. Psychodynamic Psychotherapy is based on the way children integrate and understand their experiences; everything stems from their relationships with significant others. Such integration is driven by their internal tendencies and motivations. Drucker (2009) suggests that the role of a psychodynamic therapist who works with children with autism is first to observe the child and try to comprehend their functioning, then to share their understanding of the child with the parents and the intervention team and finally to offer support to the whole family taking into account the individuality of each child. According to Muratori (2005), knowledge in the field of psychotherapy is not progressing as much compared with knowledge of psychiatric and neurobiological disorders. Furthermore, Muratori (2005) suggests that no serious attempt to study the role of psychotherapy in treating childhood autism has been carried out. With a paucity of research in this field, more empirical evidence that evaluates the efficacy of psychotherapy is needed. See Chapter Five for an in depth discussion of this type of intervention context.

1.4.3 Occupational Therapy

Occupational therapy for children addresses behaviours including play, the process of learning, self-care and social participation. Children with autism exhibit characteristics that relate to sensory integration difficulties (Walting et al 2001). The sensory integration approach was originally developed by occupational therapist Ayres (1972). Sensory integration depends on the notion that the brain operates as a coordinator and interprets sensory information (Kielhofner, 2009). Since Ayres' work (1972) a link between sensory integration and behaviour has been created. As a result, interventions based on sensory integration have been used to help children with their everyday functions (Parham, 2002). The sensory integration based approach helps children with autism integrate sensory information and it is play-based but the therapist leads the activities and changes them accordingly in order to help the child adapt in functional outcomes (Paul & Nodbury, 2012). Occupational therapists study the differences of sensory processing in children with autism and try to help them and their families overcome these difficulties in order to improve the quality of their functional behaviour (Provost et al, 2009). Some of the behaviours that are targeted in occupational therapy are self-stimulating behaviours that children with autism might exhibit. Such examples are rocking back and forth or other repetitive behaviours. Also, occupational therapy focuses on sensory integration deficits and on helping children with autism overcome potential difficulties adjusting to change and cope with daily routines. See Chapter Six for an in-depth discussion of this type of intervention context.

1.5 Other prominent therapies in autism that are not the focus of this study

In order to put the three types of treatment of focus in this study - speech and language therapy, psychotherapy and occupational therapy - into context, a summary of the literature for the other most common therapies in autism is provided here.

1.5.1 Behavioural Approach

Behaviour analytic approaches have now evolved and a number of different techniques and assessment strategies are used (see Table 1). One of the earliest reports of a systematic behavioural intervention for autism that was seminal to all behavioural treatment studies that followed was the article by Wolf et al (1964) where one case of a boy with autism who had behavioural treatment is discussed.

1.5.2 Interventions based on Play

According to Restal and Magill-Evans (1994) play provides a medium through which children develop skills, experiment with roles, and interact with others (see Table 2). They suggested that children with autism are disadvantaged in their use of play for these purposes.

1.5.3 Cognitive Approach

Cognitive behavioural therapy (CBT) is based on the hypothesis that cognitive deficiencies and cognitive dysfunctions lead to behavioural problems such as anxiety. The aim of the CBT is to target and change the way an individual thinks and reacts to their emotions and therefore ease the behavioural or psychological problems (see Table 3). This type of treatment is often applied to children with autism (White, 2003).

1.5.4 Social Stories

The social story intervention (Gray and Garand, 1993) is considered to be a method to

help children with autism understand social situations (see Table 4). “A social story is a short story that describes the salient aspects of a specific social situation that a child may find challenging. Social stories also explain the likely reactions of others in a situation and provide information about appropriate social responses”(Delano & Snell, 2006, p.2).

1.5.5 Pharmaceutical Interventions

Many parents seek pharmaceutical interventions for their children in order to treat autism (e.g. risperidone, methyl B12). Lemmon et al (2011) reported that risperidone is prescribed commonly to children of many ages, with aggression being the most common indication for treatment. Methylcobalamin (methyl B12) is a commonly used treatment that has anecdotal reports of remarkable clinical improvements with few side effects (see Table 5).

Table 1. Behavioural Approach

Study	Country	Description of sample	Type of treatment	Key findings
Baker-Erikzen et al (2007) Naturalistic study	USA	158 children with autism, aged from 24-113 months, that had a [1]Pivotal Response Training (PRT) were assessed pre- and post intervention.	[1]Pivotal Response Training	- Results showed significant improvements in adaptive functioning. - Younger children showed the least improvements at intake and the most improvement post-intervention
Coolican et al (2010) Single-subject study	Canada	8 pre-schoolers with autism and their parents were assessed before, immediately after and 2-4 months after training	Pivotal Response Training	- Children's communication skills increased - Strong relationship between parents' increased ability to implement PRT - Improvement in the children's communication skills
Hayward et al (2009) Comparison controlled study	UK	Two groups of children: 1) intensive clinic based treatment model with all treatment personnel (N=23). Mean age at treatment start was 36m 2) intensive parent managed treatment model with intensive supervision only (N=21). Mean age at treatment start was 34m. All children were assessed at intake and 1 year after treatment (5 left treatment)	[2]Applied Behaviour Analysis (ABA)	- Children improved significantly from both groups on IQ, visual-spatial IQ, language comprehension, expressive language, social skills, motor skills and adaptive behaviour - No significant differences were found between the two groups

[1] PRT focuses on increasing the child's motivation to communicate, using the principles of applied behaviour analysis in play and other natural daily-life settings (R.L. Koegel et al., 1989; R.L. Koegel & L.K. Koegel, 2006).

[2] Lovaas (1973), who is considered one of the pioneers in the field of behavioural interventions and father of the Applied Behaviour Analysis therapy (ABA), found that by punishing and reinforcing certain behaviours of children with autism significant improvement was produced in the areas targeted during the intervention. Using the principles of operant conditioning ABA encourages appropriate behaviours and helps children decrease the negative ones.

Eikeseth et al (2002) Comparison controlled study	USA	Children with autism assigned to two groups: 1) behavioural treatment (N=13) 2) eclectic treatment (N=12) Children in both groups aged 4-7 y; they were assessed at intake and 1 year after treatment began	Applied behaviour Analysis (ABA)	- The children that received ABA showed greater improvements in the areas of IQ, language and adaptive behaviour after 1 year evaluation
Eikeseth et al (2007) Comparison controlled study	USA	Same participants as in Eikeseth et al (2002). In this follow-up the mean age of children was 8y, 2m. The mean time between treatment onset and this follow-up was 31.4m in the ABA group and 33.3m in the eclectic group	Applied behaviour Analysis (ABA)	- The ABA group showed greater improvements at follow-up
Ingersoll and Lalonde (2010) Single-subject study	USA	4 children with autism (35-41 months) who were participants of a larger RCT testing the efficacy of Reciprocal Imitation Training for teaching imitation skills in young children with an ASD. As part of this study the children were assessed pre-treatment, post-treatment and at 2-month follow-up	[3]Reciprocal Imitation Training	- 3 of the 4 children showed greater improvements in their use of appropriate language after gesture imitation had started - All children exhibited generalized improvements in language skills that were maintained after the intervention was completed on both an observation assessment as well as parent reports
Smith et al (2010) Naturalistic study	Canada	45 children with autism (aged 2-6 years in the beginning of treatment) were followed for 12 months	Nova Scotia early intensive behaviour intervention model-NSEIBI (Bryson et al, 2007), that combines parent training	- Improvements in targeted domains of development, thus language and communication but also in cognitive, adaptive, problem behaviours along with

[3] Reciprocal Imitation Training (RIT) is a naturalistic intervention that was developed to teach object imitation skills to young children with autism within on-going play interactions. This intervention is drawn from the naturalistic behavioural literature and shares many common elements with interventions, such as incidental teaching (Hart & Risley,1968; McGee et al.,1983), milieu teaching (Alpert & Kaiser,1992), and pivotal response training (Koegel et al.,1987), designed to teach language skills in the natural environment.

			and Pivotal Response Training	autism symptoms

Table 2. Interventions based on Play

Study	Country	Description of sample	Type of treatment	Key findings
Francke and Geist (2003) Case study	USA	Play skills were taught to a 3 year old male diagnosed with autism and global delay	[4]Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) and free play	- Increase in the amount of complex types of play that he had with various toys - Increase in his opportunities to play with typically developing peers in a meaningful and more interactive way - Increase in his social interactions with typically developing peers
Josefi & Ryan 2004 Case presentation	Israel	6 year old boy with severe autism was observed during 16 play sessions	Non-directive play	- Non-directive play improves all four investigated aspects of attachment: autonomy, symbolic play, development and nurture -
Kasari et al (2006) RCT	USA	58 children with autism aged 3 and 4 years, who were randomized to a	Toy play	- Both intervention groups improved significantly over the control group on certain behaviours

[4] The TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) program (Schopler, 1970) is a comprehensive structured teaching approach designed for individuals with autism and communication disabilities and their families.

		joint attention intervention, a symbolic play intervention, or control group. Both structured assessments of joint attention/play skills and mother-child interactions were collected pre- and post intervention		- Children in the joint attention intervention group initiated significantly more showing and responsiveness to joint attention on the structured joint attention assessment and more child-initiated joint attention in the mother-child interaction - Children in play group showed more diverse types of symbolic play in interaction with their mothers and higher play levels on both the play assessment and in interaction with their mothers
Pajareya and Nopmaneejumruslers (2011) RCT	Thailand	32 children with autism, aged 24-72m were divided into two groups based on age and symptom severity: 1) Typical behavioural treatment 2) DIR Floortime	[5] Developmental, Individual Difference, Relationship-based (DIR®) Model	- No significant change in the Function Emotinal Assessment Score - Significant improvements in the intervention group with respect to autism symptom severity - Significant improvement in engagement and communication compared to those who received routine behavioural interventions

Table 3. Cognitive Approach

Study	Country	Description of sample	Type of treatment	Key findings
Chalfant et al (2007) Controlled trial study	Australia	47 children with high functioning autism aged 8-13 y assigned to two groups: 1) Treatment group 2) Waiting list control group 4 groups (8-10 children per group) were treated for 5 ½ months	Cognitive behavioural therapy (CBT)	- The results reported significant differences pre- and post treatment in anxiety symptoms
Reaven et al (2009) Controlled trial study	USA	33 children aged 8-14y with high functioning autism and their parents.	Cognitive behavioural therapy (CBT)	- Significant reductions in parent reports of anxiety symptoms after the delivery of

[5] The Developmental, Individual Difference, Relationship-based (DIR®) Model (Greenspan and Wieder, 1980) focuses on promoting development by encouraging children to interact with parents and others through play.

		Parent child dyads were assigned to two groups: 1) Active treatment condition 2) Wait list control condition The first 10 parent–child dyads entered treatment immediately. Additional families were put on waitlist and after 3 months they were asked to enter treatment. These participants eventually engaged in post-treatment and follow-up assessments in a similar manner as the initial treatment group, thus 23 of 33 families served as their own controls		the group treatment, compared to the wait list control group
Storch et al (2013) Randomized Controlled Trial	USA	45 children (7-11y) with high functioning autism and anxiety were randomized to receive 16 sessions of weekly CBT or treatment as usual for an equivalent duration. Assessments were conducted at baseline, post-treatment and at 3month follow-up	CBT	- Children receiving CBT showed substantial improvement relative to treatment as usual group on primary anxiety outcomes. - Gains were maintained at follow-up.
Wood et al (2009) Randomized Controlled Trial	USA	40 children (7-11y) with autism and anxiety disorder were randomly assigned to 16 sessions of CBT or a 3-month waitlist (36 completed treatment or waitlist). Families were assessed at baseline and post-treatment/post-waitlist	CBT	- Positive treatment response at post-treatment evaluations and benefits were maintained at 3m follow-up

Table 4. Social Stories

Study	Country	Description of sample	Type of treatment	Key findings
Crozier and Tinconi (2007) Single-subject study	USA	3 children with autism aged 3-5 y were assessed pre- and post the implementation of social stories at school	Social Stories	- Reduction of inappropriate behaviours - An increase in appropriate behaviours was found across all participants
Delano and Snell (2006) Single-subject study	USA	3 children with autism and 6 typically developing peers. Each target student with autism was paired with a same-age peer for the intervention sessions. Target students were paired with a second peer for generalization probes. The participants were assessed prior the first experimental session and during treatment at several time points	Social Stories	- The use of Social Stories may lead to the benefits of increased social engagement with peers and the frequency of initiating comments and responding to peer initiations
Ozdemir (2008) Single-subject study	Turkey	3 children with autism (7-9y) were assessed at baseline and at different time points during intervention	Social Stories	- Effective in decreasing disruptive behaviours
Schneider and Goldstein (2010) Single subject study	USA	3 kindergarten to 5th grade students with autism were assessed pre- and post intervention. The children were assessed at baseline during treatment and at follow-up.	Social Stories (a visual schedule using pictures of social stories was added at follow-up)	- Improvement in on-task behaviours for all children - The participants (after intervention) were able to respond more appropriately and manage their behaviours - Social Stories facilitated the development of self-management - Further improvement was reported at follow-up suggesting that visual schedules may be an effective way to improve social stories further

Table 5. Pharmaceutical Interventions

Study	Country	Description of sample	Type of treatment	Key findings
Bertoglio et al (2010) Double-blind, cross-over clinical trial	USA	30 children (3-8y) with autism completed the 12 week double-blind study. All participants received 6 weeks placebo and 6-week of methB12 and 22 subjects completed the 6 month extension study	Methylcobalamin B12	Comparison of the overall means between groups suggests that it is ineffective in treating behavioural symptoms of autism
Ghaeli et al (2014) Open-label study	Iran	15 children with autism aged 4-17 y were treated with risperidone for 8 weeks	Risperidone	- Study showed that social interactions and verbal communication skills were significantly improved after treatment Stereotypic behaviours did not change
McCracken et al (2002) Multisite double-blind Randomized Controlled Trial	USA	8 weeks of treatment with risperidone versus placebo in 101 children (5-17 y)	Risperidone	- Effective in reducing tantrums, aggression or self-injurious behaviours in children with autism

1.6 Research questions and justification

This study aims to answer the following questions:

- Do children with autism show significant development in communication and social skill, regardless of intervention context?
- Does the pattern of development differ across children in the UK and Greece, regardless of intervention context?
- Do patterns of development differ in the UK and Greece for children in the same intervention context (i.e. SLT based interventions)?
- Does the specific country and intervention context associate with the pattern of developmental change?

If research and practice in the treatment of children with autism are to improve, then increasing the number and quality of studies exploring the development of children with autism over time should increase. The need to explore comprehensive and effective treatment plans is essential in order to serve children with autism and their families in the most efficient way. Also, investigating the effects of different types of treatment is likely to be of benefit to many children and their families. It is important to assess different types of treatment and to identify those characteristics that predict responsiveness to specific programmes/approaches. It is also equally important to raise awareness of various types of treatment, to offer insight to parents about the development of autism over time and help professionals expand their understanding with respect to the manifestation of autism throughout time. Moreover, it is essential to add to the literature on psychotherapy due to the scarcity of empirical support in the field of psychodynamic/psychoanalytic psychotherapy.

The purpose of this study is to identify the progress of children with autism over time in the UK and Greece and directly compare progress following different

types of therapy. Also, the differences in the development of children with autism between the two countries will be identified.

One area of progress in the diagnosis and epidemiology of autism across countries has been at the level of screening tools that can be validated in numerous languages and dialects. Nevertheless, there are very few cross-national studies (Lotter, 1978; Probst, 1998) that address the impact of culture on autism. There is also very little information about how the genetics, biology, risk factors, treatment and course of autism differ across countries, continents or ethnic groups (Yeargin-Allsopp & Boyle, 2002). As mentioned by Cascio (2015), most of the literature on autism has focused on major English speaking countries, like the United States, Canada, UK and Australia. The main comparisons between these countries refer to their policies (e.g. Baker & Stokes, 2007). Further research has been carried out in other countries, like India (Daley, 2002,2004), Italy (Cascio, 2015; Cola and Crocetti, 2011) and France (Chamak et al, 2010). For example, Cascio (2015) investigated how autism is conceptualized in various autism intervention services offered in Italy. However, no previous research has been conducted comparing the outcomes of the three different approaches of treating childhood autism in the UK and in Greece and therefore the findings will be of direct clinical and theoretical interest. Whilst the attempts to raise awareness, early identification and diagnosis of autism advance, research about how children develop and how different types of treatment affect them is needed in order to create more appropriate ways to support children with autism and their families.

1.7 Thesis Format

The aim of this introductory chapter is to set the context of the thesis as well as acquaint the reader with the main topic of the study. Hereby follows a structured

outline of each of the remaining chapters of the thesis.

In the second chapter the literature on the development of children with autism over time and more specifically on longitudinal and prospective studies of children with Autism Spectrum Disorders is reviewed.

The third chapter explores healthcare provision and service provision for autism in the UK and in Greece. The main similarities and differences in regards to autism and the history of service provision between the two countries are identified.

The fourth, fifth and sixth chapters provide an overview of studies related to three specific types of treatment of childhood autism: speech and language therapy, psychoanalytic/psychodynamic psychotherapy and occupational therapy.

The seventh chapter describes the methodological approach adopted by the study. The aim of this chapter is to provide a critical discussion of the methodology, methods and ethical issues related to the study. The context of the settings will be outlined and the research design, methods and procedure will be described.

The eighth chapter presents findings in four main sections: Exploration of associations between different skills and their developmental trends over time for the whole group; examination of development across different countries ; examination of the effects of country and intervention context on change over time ;subgroup analysis of the effect of country on those with the same therapy context (SLT) and the effect of therapy context on children in the same country.

Finally, chapter nine discusses the findings of the research. Limitations of the study and implications for further research and practice are also considered in this chapter.

Chapter 2 Development of children with autism over time

Autism is a lifelong developmental disorder that affects individuals in various ways. It is important to explore the manifestation of core symptoms of autism through childhood and later on and to monitor the status of autism diagnoses. The aim of this review is to highlight the key evidence currently available regarding the development of children with autism over time. Understanding the nature and trajectory of change in various aspects of development may help in the earlier detection of autism, and consequently promote earlier intervention.

This chapter is organised around the following aims: 1) to provide an overview of studies on the general development of children with autism, on autism severity trajectory, repetitive behaviours and language; 2) to identify limitations within this body of research. This review was based on a search of published empirical research studies available since 2000 in order to provide the most up-to-date information. Available research was reviewed in an attempt to locate the studies that met the aims previously stated and studies were excluded if their focus was on other aspects of autism.

The diversity in the developmental trajectories and rates of change among children with ASD is illustrated here. As suggested by Matson & Sturmey (2011) the study of changes in the development of children with autism has been quite limited but it is shown from the existing literature that symptoms of autism do change over time (Matson & Sturney, 2011). Understanding the nature and trajectory of change in various aspects of development may help in the earlier detection of autism, and consequently promote earlier intervention. Most of the literature summarized in this chapter focuses on longitudinal and prospective studies of *preschool* children with Autism Spectrum Disorders, but a small body of literature concerns adolescents and

young adults. The chapter will focus on general development and severity, repetitive behaviours and language although it is acknowledged that other areas of development have been documented.

Children with autism are considered to be very different from each other and the clinical presentation of their symptoms varies along with the outcomes following an intervention (Ben-Itzchak et al, 2014). According to Howlin et al (2009) some children demonstrate significant progress in different areas of development while others might present with no or less significant improvements when assessed with standardized measures. Most studies included in a review by Seltzer et al (2004) reported a positive change in the severity of autism symptoms over time. However, stability in autism diagnosis is often documented across early childhood and into adolescence (McGovern & Sigman, 2005), thus there is mixed evidence. For example, research suggests that maladaptive behaviours decrease over time along with challenging behaviours for some but not all children. Gray et al (2012) identified an improvement in some of their participants over time, but a 23% showed no change and a 16% presented with an increase in their maladaptive behaviours.

In two projects (Lindsay et al, 2010; Meschi et al, 2010) of the Better Communication Research Programme (BCRP; Dockrell, Lindsay, Law, & Roulstone, 2014)[6] the focus was on the progress of children with ASD or speech, language and communication needs (SLCN) who go through the mainstream education system. In the Meschi et al (2010) study significant movement into and out of the categories of SLCN and ASD was reported, especially when the children were moving between primary and secondary school. However, less movement was reported in children

[6] The Better Communication Research Programme (BCRP; Dockrell, Lindsay, Law, & Roulstone, 2014) was commissioned as part of the Better Communication Action Plan, the government's response to the Berkow (2008) review of services for children and young people with speech, language and communication needs.

with ASD. More specifically, 41% of the children who were in the ASD category when they started secondary school remained in the same category of need when they finished secondary school.

Tables 6-11 show studies that have been completed since 2000 regarding change in autism over time. Most of the studies were conducted in the USA, five in Canada, four in the UK, two in Australia, two in France, one in Italy, one in Iceland and one in Netherlands.

2.1 The general course of autism and diagnostic status

There is research that suggests that children with autism exhibit different trajectories. For example, Gotham et al (2012) suggested that some children with autism could improve over time with respect to their symptoms while others might delay in demonstrating any improvement. It can be seen though that the majority of the studies that focus on the manifestation of autism over time do not take into consideration how the therapy context might have influenced the developmental pattern of the children, which my thesis aims to investigate.

Szatmari et al (2015) carried out a large prospective outcome study, in order to assess the developmental trajectories of autistic symptom severity (like restricted and repetitive behaviours or social communication impairments) and level of adaptive functioning (acquisition of various skills and abilities that are developmentally suitable). A cohort of 421 preschool children with ASD was monitored at 4 time points (at baseline, at 6 months and 12 months after baseline, and at age 6 years). The authors identified heterogeneity in the development of children with ASD. With respect to the progress of their adaptive functioning the results showed improvement in 20% of the sample and an 11% of the children demonstrated a decrease in autistic

symptom severity during the study. These findings are consistent with research by Gotham et al (2012) and Fountain et al (2012). Furthermore, the researchers suggested that the female sex was linked with less severe symptoms and better progress and that there was an association between younger age at diagnosis and the higher functioning group. Nonetheless, the results are weakened by the fact that they did not explore the intervention contexts of the children participating and the effect this might have on the developmental trajectories.

A prospective study on the psychological development of 219 children with autism, aged between two and seven years old, by Baghdadli et al (2006) also report significant changes over a period of 3 years. Developmental regression was observed in their daily living skills and person-related cognition but there was stability in other areas such as communication, socialization and object-related cognition. It is also interesting to note that a link was found between the absence of speech in childhood and poor outcomes. However, this finding should be interpreted with caution since it could be the effect of comorbidity with functioning level.

The changes in the developmental areas mentioned earlier seemed to be associated with the children's level of psychological functioning, with their language skills and the severity of their symptoms. More specifically their initial functioning level could be considered as a predictive factor of their psychological development. These results have important implications for services providing therapy for children with autism since they may help understand further the variables that mostly affect the development of children with autism.

Eaves & Ho (2004) followed forty-three children diagnosed with autism or pervasive developmental disorder not otherwise specified (PDD/NOS) from 2,5 years to 4.5 years and based on the results 79% stayed in the same diagnostic category. In

addition, children with milder symptomatology and higher non-verbal skills in relation to verbal ones exhibited the most improvement in verbal skills. The Childhood Autism Rating Scale (CARS; Schopler et al, 1988) scores in this study remained the same between mean ages 2 years 9 months and 4 years 11 months.

On the other hand, Jonsdottir et al (2007) did not replicate this finding in a sample of preschool children with autism. Jonsdottir et al (2007) explored the progress of forty-one children with pervasive developmental disorders (PDDs) twice during their preschool years (3-6 years old). The mean period of time between the two times that the children were assessed was 27.71 months. The participants were also receiving intensive eclectic intervention on average about 30 hours per week. The results of the study showed that with respect to their cognitive performance the children remained stable but the symptoms of autism decreased. For direct assessment of behaviour, the CARS was used and the scores decreased over time. A possible explanation about the difference in these results compared to the ones reached by Eaves and Ho (2004) could be that the participants in the Eaves and Ho (2004) study were more cognitively impaired and did not have the chance to change significantly in that period of time.

In a similar vein, Charman et al (2005) followed twenty-six children with autism aged 2 years to the age of 7 years. The results showed that 85% retained their diagnosis and symptom severity showed different trajectories in the different symptom domains over time. Also, improvements were detected for some children in competencies and in terms of symptom impairments. However, compared to the previous study by Eaves & Ho (2004), Charman et al (2005) did not find age 2 performance on standard measures of cognitive skills, language skills and symptom severity to be predictive of age 7 functioning in these domains, but at age 3 they did

predict future outcomes. Nonetheless, it should be taken into account that these findings might have resulted from the use of a younger sample at initial diagnosis compared to the Eaves and Ho (2004) study.

Sutera et al (2007) argues that children can lose their autism diagnosis over time, after they evaluated children with ASD at 2 and 4 years of age. In the Sutera et al (2007) study, 73 two-year olds with ASD were assessed on a battery of standardized measures of cognitive and adaptive functioning and were reassessed when they were 4 years old. Based on the findings thirteen of the children lost their autism diagnosis by age 4. However, not enough information was provided about the effect of the intervention that the children received during that period.

The diagnosis of autism was reported as less stable between the ages of 2 and 4 years in a study by Turner & Stone (2007). The researchers followed forty-eight children diagnosed with autism or PDD-NOS starting at age 2 until they were 4 years. In this sample 63% of children retained the diagnosis of autism at age 4. A possible explanation for these findings is the use of different diagnostic measures at ages 2 and 4.

In a prospective study of 87 high risk (siblings of children with autism) and low risk infants (no history of autism), Landa & Garret-Mayer (2006) assessed the general development of the participants from 6 to 24 months of age. This study included three outcome groups: ASD group, language delayed group and typically developing group. Results demonstrated that at 14 months the performance of the children who were later diagnosed with autism was worse with respect to language and motor skills, in comparison to the group that went on to develop typically. Moreover, by 24 months the children with autism scored lower in the non-verbal problem solving domain compared to the typically developing group. When compared

to the language delayed group, the ASD group performed worse in gross motor, fine motor and receptive language domains but there was no significant difference between the groups with respect to their expressive language scores. It is interesting to note that those with a later diagnosis of autism started to change gradually between 14 and 24 months and they regressed in the social and/or language areas.

In a more recent longitudinal study, Landa et al (2013) replicated and extended the findings of the study conducted earlier by Landa & Garret-Mayer (2006). Landa et al (2013) investigated the social, language, and motor trajectories in 235 children with and without a sibling with autism, aged 6–36 months. In the Landa et al (2013) study, children were grouped based on their diagnosis by 14 months of age. So, there were three groups: children diagnosed by 14 months, children diagnosed after 14 months and typically developing children. Landa et al (2013) examined the developmental features and trajectories of children with early versus later indication of autism. Furthermore, they looked into the differences between those groups and children without autism from 6 through 36 months of age. At 6 months the groups exhibited similarities in their development but after that period the groups of children that developed autism presented with atypical trajectories. The results also showed that the impairment from 14 to 24 months was greater in the group diagnosed before 14 months than the group that was diagnosed later. However, at 36 months the impairment seemed comparable between the two groups. Furthermore, developmental plateau and regression occurred in some children with autism, regardless of the time that they were diagnosed.

The results of a study by Ozonoff et al (2010) support the previous findings of the studies by Landa & Garret-Mayer (2006) and Landa et al (2013). Ozonoff et al (2010) also found that the development of the social, motor, communication and

cognitive skills of children with autism remains intact at 6 months of age and thereafter comes the regression of those skills that usually becomes more obvious around 12 months of age. Lord et al (2006) found that 89% of children with autism at age 2 received the same diagnosis at age 9 and improvements were found for some children as well. Werner et al (2005) reached similar conclusions and suggested stability of autism symptoms over time after assessing children at 2 and then 3-4 years of age.

Following Lord et al (2006), Lord et al (2012) monitored the progress of toddlers referred for risk of autism every two months from age 18 months to age 36 months. A battery of standardized observational measures (ADOS, ADI-R and MSEL) were used in order to assess sixty-five children who were consecutive referrals and thirteen children from other research projects. The results showed that forty-eight children received an ASD diagnosis and replicated the findings from the study by Landa & Garrett-Mayer (2006).

Table 6. The general course of autism and diagnostic status

Study	Country	Sample	Assessment Measures[7]	Key findings
Szatmari et al (2015) Longitudinal	Canada	421 children with ASD (2-4 y)	ADOS, ADI-R, 99-item CBC, PLS-Fourth Ed., MPR	- Possibility of improvement in adaptive functioning in 20% of the sample - 11% of the children demonstrated a decrease in autistic symptom severity
Landa et al (2013) Prospective longitudinal	USA	235 children with and without a sibling with autism aged 6–36 mo	ADOS, MSEL, Communication and Symbolic Behaviour Scales Developmental Profile (CSBS DP)	- Similarities at 6 mo in their development but after that groups of children that developed autism presented with atypical trajectories
Baghdadli et al (2006) Prospective	France	219 children with autism, aged between 2-7 y	CARS, ADI-R, VABS, EAP, WISC III , WPPSI-R or subscale of the K-ABC, French version of ESCS	- Developmental regression in daily living skills and person-related cognition - Stability in areas like: communication, socialization and object-related cognition
Lord et al (2006) Prospective	USA	192 children prospectively studied from referral for autism before 36 mo	VABS, ADI-R, MSEL, WISC, Differential Ability Scales, ADOS, PL-ADOS	- 89% of children with autism at age 2 received the same diagnosis at age 9
Werner et al (2005) Retrospective	USA	3 groups: 72 (3–4 y) with ASD; 34 (3–4 y) with developmental delay without autism; and 39 (1–4 y) children with typical development	EDI	- Stability of autism symptoms

[7] A complete list of the full names of assessment measures included in this chapter is provided in Appendix VI

Landa & Garret-Mayer (2006) Longitudinal Prospective	USA	87 children divided into 3 groups: ASD, Language delayed, typical	PLS-III or IV, ADOS, MSEL, CDI	- Significant decrease in development between years 1 and 2
Lord et al (2012) Longitudinal	USA	65 children referred for possible ASD; 13 referrals of children who were part of typically developing and language-delayed comparison groups from other projects (12 - 18 mo)	ADOS, ADI-R and MSEL	- Age of symptom onset didn't make any difference to the severity of autism - Variability in early trajectories
Sutera et al (2007) Longitudinal	USA	73 two-year old children with ASD	M-CHAT, clinical judgment, ADI-R, ADOS-G, CARS, VABS ,MSEL, BSID, 2nd Ed., DAS	- 13 of the children lost their autism diagnosis by age 4y
Ozonoff et al (2010) Prospective	USA	25 infants later diagnosed with ASD; 25 typically developing assessed at 6, 12, 18, 24, and 36 mo	Video observation	- Development of the social, motor, communication and cognitive skills of children with autism remains intact at 6 mo and thereafter comes the regression of those skills
Eaves and Ho (2004) Longitudinal	Canada	49 children (2,5 y) diagnosed with autism or PDD-NOS	PDDST, CHAT, BSID-II, Mental Scale, WPPSI-R, VABS, CARS	- 79% stayed in the same diagnostic category - CARS scores in this study remained the same between mean ages 2 y 9 mo and 4 y 11 mo
Turner & Stone (2007) Longitudinal	USA	48 two year old children diagnosed with autism or PDD-NOS	Mullen Scales of Early Learning, ADOS, ADI-R, CARS	- 63% of children retained the diagnosis of an ASD at age 4

Jonsdottir et al (2007) Longitudinal	Iceland	41 children (mean age: 41,43 mo) with pervasive developmental disorders (PDDs)	ADI-R, CARS, BSID- II, WPPSI-R, VABS	- Stability in cognitive performance - Decrease in autism symptoms - CARS scores decreased
Charman et al (2005) Longitudinal	UK	26 children with autism aged 2y at time 1	CDI, RDLS-II, GMDS, ADI-R, ADOS, VABS, structured interactional assessment	- 85% retained their diagnosis - Improvements for some children in competencies and in terms of symptom impairments
Turner et al (2006) Longitudinal	USA	26 children diagnosed with autism or PDD-NOS at age 2	BSID-II, SICD–R, CDI, K–ABC, MPR, Leiter, ADOS, ADI-R,WJ–R,WIAT, PPVT–3, EVT	- Stability of diagnosis at age 9 - Significant improvements in children's cognitive and language skills

2.2 Autism Severity Trajectory

Six trajectories were identified by Fountain et al (2012) using social and communication skills and repetitive behaviours as outcomes. The authors utilized the records of children who were born between 1992 and 2001 in California who had obtained an autism diagnosis by 2006. The data were available on outcomes only up to 2006. The sample population consisted of 6975 individuals from whose records the researchers obtained the trajectories along with demographic information. They used group-based latent trajectory modelling and multinomial logistic regression models in order to identify and describe subgroups within the data that had similar developmental trajectories. Significant heterogeneity in the trajectories was noted based on the results and they also identified a group of children that started at baseline with the lowest scores and improved substantially. The researchers also mentioned that among these children the most likely to progress were those without intellectual disability and with more educated, non-minority mothers. However, the specific factors, through which the socioeconomic status influenced the developmental trajectories were not explored, and no information was provided regarding the types and quantities of services that individual children used. Similar findings were reached by Gotham et al (2012) who identified four trajectories for autistic symptom severity in a sample of 345 children (aged 2-5 years old) with ASD, who were followed until they were 15 years old. Gotham et al (2009) had developed a standardized metric of ADOS calibrated severity scores (CSS) that are more uniformly distributed across ages and language levels than ADOS raw scores (Venker et al, 2014, p. 547). Gotham et al (2012) used a battery of standardized tests and the ADOS calibrated severity scores (CSS) were analysed. The aim of the study was to identify latent trajectory classes or patterns of change in ASD severity over time in prospective repeat-

assessment data. Based on the findings there was stability in the ASD symptoms over time and only 15% of the sample was assigned to improving or worsening classes. In addition, an association between differences in language and daily living skills and differential trajectories of autism severity was suggested.

Venker et al (2014) aimed to replicate and extend Gotham et al (2012) findings by investigating the autism severity trajectory classes in early childhood. The participants were 129 children between 24 and 36 months referred for possible autism or diagnosed with ASD and their evaluations were carried out at age 2½; 3½; 4½ and 5½. The researchers identified four differential trajectory classes of autism severity (persistent high, persistent moderate, worsening and improving) and based on the results it was suggested that there was little change in overall severity level during early childhood. Contrary to Gotham et al (2012), Venker et al (2014) did not find an association between the gender, ethnicity or assignment to a certain trajectory class of autism severity. However, their sample had limited racial and ethnic diversity. Furthermore, significant differences in functional skills trajectories by class were demonstrated and it was suggested that early non-verbal cognition impairment along with deficit in daily living skills might predict a persistent and severe trajectory of autism severity. However, as it is noted by the authors due to the observational methods used in the study they cannot be definite whether increased autism severity leads to decreased functional skill levels or if lower functional skills lead to more severe autistic symptoms.

Table 7. Autism Severity Trajectory

Study	Country	Sample	Assessment Measures	Key findings
Fountain et al (2012) Prospective	USA	Records of 6975 individuals born between 1992 and 2001 and were diagnosed with autism by 2006	CDER	- Significant heterogeneity in the trajectories - A group of children that started at baseline with the lowest scores improved substantially
Gotham et al (2012) Longitudinal	USA	345 children (aged 2-5 y) with ASD	ADOS, ADI-R, VABS	- Stability in the ASD symptoms over time - Association between differences in language and daily living skills and differential trajectories of autism severity
Venker et al (2014) Longitudinal	USA	129 children aged 24-36 mo referred for possible autism/diagnosed with ASD	ADOS, ADI-R, MSEL, PLS-4	- 4 differential trajectory classes of autism severity - Little change in overall severity level during early childhood - Significant differences in functional skills trajectories by class

2.3 Development of autism during adolescence and young adulthood

There is growing body of literature that reports a decrease of autism symptoms during adolescence and young adulthood (e.g. Fecteau et al, 2003; Seltzer et al, 2003; Shattuck et al, 2007). However, in a study by Shattuck et al (2007), the improvement between middle childhood and adolescence was slower when compared to early and middle childhood. Anderson et al (2011) also suggested that there is a slower improvement in individuals with autism during adolescence. In Seltzer et al (2003) and Shattuck et al (2007) studies it was found that repetitive use of objects, measured by the ADI-R, declined with age in children and adults. Nevertheless, it should be kept in mind that adolescence is considered to be a difficult period for children with autism (Anderson et al, 2011). Findings from a number of studies (Anderson et al, 2006; Posey et al, 2006) of children with autism suggest that various vulnerability factors in adolescence could lead to increased withdrawal. Also, during adolescence the access to community activities and services usually changes, along with the availability and intensity of the treatments. In early childhood, the therapy that is provided can be intensive and focused but during adolescence and adulthood it might lose these features and this may influence the development of individuals with autism (Bagdhali et al, 2012). Therefore, these factors can affect the results of the studies that look into the development of children with autism during adolescence.

Seltzer et al (2003) conducted a retrospective study in order to assess the development of autism over time. The participants of their study were older than the study groups seen earlier; 400 individuals who had been diagnosed with autism were divided into two cohorts: adolescents (10–21 years) and adults (22 years or older). Seltzer et al (2003) looked into the differences between current symptoms and lifetime symptoms, like childhood functioning, especially at age 4 to 5 years. Seltzer

et al (2003) found that the symptoms of autism decreased over time. Nonetheless, the degree of improvement was not the same across groups and it depended on the areas of behaviour that were taken into consideration. These results further support the findings of other longitudinal studies that reported improvements in communication, on average, from childhood to adolescence and adulthood (Howlin et al, 2004). However, there are other domains of development that do not improve significantly. Seltzer et al. (2003) found that most of their sample of adolescents and adults (87.7%) with autism met the diagnostic criteria for autism in the domain of restricted, repetitive behaviours and interests. However, this percentage was significantly lower than the 97% who met criteria at an earlier point in their lives.

Similar conclusions as Seltzer et al (2003) were reached by Howlin et al (2004) who found that most of the adults that participated in their study showed that only 12% of the group were symptom free in the behavioural domain and the rest showed mild (42%), moderate (35%), or severe (11%) behavioural symptoms. According to Howlin et al (2004) the lower the language skills, the less the improvement over the years.

In three studies (McGovern & Sigman, 2005; Seltzer et al, 2003 and Woodman et al, 2015) it was reported that adults with intellectual disability and ASD tend to show fewer improvements over time. Woodman et al (2015) used a prospective longitudinal design to explore developmental trajectories of autism symptoms and maladaptive behaviours in adolescents and adults with ASD. Maladaptive behaviours included self-injurious behaviours, withdrawal, uncooperative behaviour, aggression and destruction of property. The sample in the study included 313 adolescents and adults with ASD. The findings suggested an overall improvement in the individuals over time and a decrease in autism symptoms

was identified. However, positive change was not seen in all the participants, since some of them had worsening symptoms during the study. Woodman et al (2015) found greater impairment in restricted and repetitive behaviours and interests (RRBs) and verbal communication followed by impairment in social reciprocity. Most of the participants presented with less maladaptive behaviours over the 8-year period but still some of the adults showed worsening behaviours.

McGovern & Sigman (2005) and Chowdhury et al (2010) reached similar findings to the ones reached by Seltzer et al (2003) and Woodman et al (2015). In the Chowdhury et al (2010) study the Autism Diagnostic Interview-Revised (ADI-R; LeCouteour, Lord and Rutter, 2003) and the Repetitive Behavior Scale-Revised (RBS-R; Bodfish et al, 2000) were used to explore restricted and repetitive behaviours (RRBs) in 34 high functioning adults with ASD and an overall improvement in these individuals over time along with a decrease in their autism symptoms was found.

In the study by McGovern & Sigman (2005) forty-eight children with autism were observed in both early and middle childhood and later on in late adolescence using the Autism Diagnostic Interview-Revised (ADI-R; LeCouteour, Lord and Rutter, 2003) and the Vineland Adaptive Behavior Scale (VABS; Sparrow et al, 1984). The results suggested that the developmental trajectory from early childhood to adolescence appeared to show positive change in social interaction skills. Even though the diagnosis did not change the parents of the participants observed improvements in adolescence. A positive link between social involvement with peers and adaptive behaviour skills was also found.

Anderson et al (2009) assessed a sample of children over an eleven-year period from toddlerhood to adolescence. The sample consisted of 93 children with autism; 51 with PDD-NOS and 46 with developmental delay but not autism. The

authors reported positive changes overall in the autism group as their adaptive social abilities increased over time, social deficits decreased and their nonverbal IQ improved. It was also noted that children with autism benefited from early intervention. Additionally, it was suggested that early childhood characteristics, e.g. diagnosis, cognitive abilities, environmental resources could predict the growth of adaptive social skills form age two to thirteen. Nonetheless, the results could be stronger if the families were randomly assigned to treatment or if the quality of treatment had been controlled or measured.

In an effort to further investigate change in the development of children with autism, Bagdhali et al (2012) followed 152 children with autism from childhood to adolescence over a ten-year period. Progress was noted in their Daily Living Skills and there were changes in socialization and communication abilities too. Furthermore, the results showed that fewer hours of early intervention were linked with a lower trajectory of communication. This finding is in agreement with the results of the previous study by Anderson et al (2009) who also found an association between hours of therapy and the impact it has at adolescence.

Kelley et al (2010) assessed three groups of children: 13 children that had been diagnosed with autism on average eight years prior to the study and they no longer met criteria for a diagnosis on the spectrum based on their ADOS scores (Optical Outcome-OO); 14 children who still retained their diagnosis (High Functioning Autism-HFA) and 14 typically developing. The children were 11-84 months of age when they received their initial diagnosis of autism and they were re-assessed when they were 11-12 years old. Their findings indicated that the OO group scored lower in the communicative, social and behavioural domains compared to the typically developing group but their scores were still in the normal range. The HFA

group though continued to show impairments in these areas. There is also speculation by the authors that early behavioural intervention might have contributed to the improvement of the OO group, since 8 of the 13 children for whom they had treatment data received intensive behavioural treatment but only two from the HFA group had received this type of treatment. Stability in autism diagnosis was suggested in a study by Turner et al (2006) who assessed the developmental outcomes of children 7 years after their initial diagnosis. The participants of the study were 26 children diagnosed with autism or PDD-NOS at age 2 who received follow- up evaluations at age 9. Based on the results the diagnosis of autism or PDD-NOS that children received at age 2 was more likely to remain the same at age 9. However, with respect to the children's cognitive and language skills, the findings suggested that there was a significant improvement between the ages 2 and 9. Furthermore, the results suggested that children in the higher outcome group received an earlier diagnosis and had more speech and language therapy between ages 2 and 3 than did children in the lower outcome group.

Table 8. Development of autism during adolescence and young adulthood

Study	Country	Sample	Assessment Measures	Key findings
Seltzer et al (2003) Retrospective	USA	400 individuals with autism: adolescents (10–21 y) and adults (22 y or older).	ADI-R	- Symptoms of autism decreased over time - Adults with intellectual disability and ASD tend to show fewer improvements over time
Woodman et al (2015) Longitudinal Prospective	USA	313 adolescents and adults with ASD	ADI-R, SIB-R, WRIT, VS, Positive Affect Index, FMS	- Overall improvement over time - Decrease in autism symptoms - Less maladaptive behaviours over the 8-year period but still some of the adults showed worsening behaviours - Link between positive family relationships and interactions with positive outcomes for adults with ASD
Bagdhadli et al (2012) Longitudinal	France	152 children with autism (average age: 5 y)	CARS, ECPA, WISC III, WPPSI-R or subscale of the K-ABC, ABC, Familial Resources Index	- Progress was noted in the children's daily living skills - Changes in socialization and communication abilities - Fewer hours of early intervention were linked with a lower trajectory of communication
Anderson et al (2011) Prospective Longitudinal	USA	Data of 116 participants assessed between 9 -18 y. 65 children with autism; 27 with broader autism spectrum disorder; 24 with developmental disability but not	ADOS, ADI-R, WISC-III, DAS, MSEL, ABC, PDS, parentalreports, CBCL, ABCL, DBC, ALS	- Hyperactivity behaviours improved the most for the autism group - Social withdrawal became worse over time for the autism group

		autism		- Greater heterogeneity in trajectories for maladaptive behaviours in autism group
Anderson et al (2009) Longitudinal	USA	93 children with autism; 51 with PDD-NOS and 46 with developmental delay but not autism assessed from age 2-13 y	ADI-R, ADOS, VABS, MSEL or MPR, SICD-R, parental reports	- Adaptive social abilities increased over time, social deficits decreased and nonverbal IQ improved in the autism group
Howlin et al (2004) Longitudinal	UK	68 participants referred for autism in childhood (average age at referral: 7 y)	ADI, parental reports, WAIS-R or Raven's or the Leiter or MPS ,BPVS, NARA, Schonell Spelling test	- IQ scores tend to remain relatively stable over time
McGovern & Sigman (2005) Longitudinal	USA	48 children with autism observed from early childhood-adulthood	ADOS, ADI-R, VABS	- Positive change between developmental trajectory from early childhood to adolescence and social interaction skills. - Stability in diagnosis but the parents observed improvements in adolescence.
Kelley et al (2010)	USA	3 groups: 13 had lost their autism diagnosis (Optical Outcome group); 14 typically developing and 14 with high functioning autism. (11-84 mo at diagnosis)	ADI-R, ADOS-G, VABS, BASC, subscale of WISC 4th Ed., PPVT-3d Ed., subtest of the TLC, TOPL, CASL-3d Ed.	- HFA continued to show pragmatic, linguistic, social, and behavioral difficulties - OO group overcame their social, communicative and behavioural difficulties
Chowdhury et al (2010) Retrospective	USA	34 individuals aged 19-28 y	ADI-R, RBS-R	- Improvements in the RRB domain as a whole, with the exception of Self-injurious Behaviours

2.4 Parental behaviour and development of autism

As well as some of the factors arising from studies above, research suggests that another factor that might influence the development of individuals with ASD is the behaviour of their parents (Baker et al, 2011; Greenberg et al, 2006; Woodman et al, 2015). Woodman et al (2015) highlighted the importance of family process to individuals with ASD, since they found that improvements in the relationship between mother and child led to a decrease in deficits in social reciprocity and asocial behaviours. Thus, a link between positive family relationships and interactions with positive outcomes for adults with ASD was reported. Woodman et al (2015) suggested that maternal warmth, praise and mother-child relationship quality affected the development of children with autism in an 18-month period, but as the authors mentioned there was not enough information about the reverse direction of effects. In addition, it should be taken into consideration that the mothers included in the study came from a similar socioeconomic background; they had completed 16 years of education on average and 67% were employed. Therefore, the results might be different if there were varying socioeconomic backgrounds.

Baker (2011) investigated the period from early adolescence to young adulthood and the relationship between the adaptability of a family (ability to remain flexible) and the development of children with autism during that period. Their participants were the same as in the Seltzer et al (2003) and Greenberg et al (2006) studies. More specifically, they came from a longitudinal investigation of families of adolescents and adults with autism in Massachussets (n=204) and Wisconsin (n=202). The Baker (2011) results suggest that the level of family adaptability might influence the development of the children's behaviour problems. Similarly in the Greenberg et al (2006) study a relationship was found between high level of criticism and

increasing severity of RRBs along with more internalizing and asocial maladaptive behaviours. However the fact that the studies (Baker, 2011 and Greenberg et al, 2006) were based heavily on maternal reports add a cautionary note about the strength of the results.

Table 9. Parental behaviour and development of autism

Study	Country	Sample	Assessment Measures	Key findings
Baker et al (2011) Longitudinal	USA	149 families of children diagnosed with autism (10-22 y)	FACES II,PAI, SIB-R, CES-D,WRIT, VSC	- The level of family adaptability might influence the development of the children's behaviour problems
Greenberg et al (2006) Longitudinal	USA	149 mothers who lived with their son or daughter with autism aged 11.3 to 48.9 y at Time 2	Five-Minute Speech, SIB-R, ADI-R	- High levels of criticism related to increasing severity of RRBs along with more internalizing and asocial maladaptive behaviours

2.5 Restricted and Repetitive Behaviours and interests (RRBs) over time

The heterogeneity that characterizes children with autism also defines the development of restricted and repetitive behaviours and interests, which vary among children with autism. Restricted and repetitive behaviours and interests (RRBs) are common among many children with autism and they are interpreted as repetitive mannerisms, intense preoccupations with specific objects/parts of them, specific routines and behaviours based on sensorial interests (Richler et al, 2007). However, not all children with autism present with these behaviours over time extensively (Walker et al, 2004). RRBs have been divided into two forms: lower order and higher order behaviours (Turner, 1999). Based on Harrop et al (2014) the lower order ones are defined as "repetitive motor actions and movements and physical and/or sensory manipulation of objects and the higher order ones include more advanced cognitive functions and are characterized by the presence of routines" (Harrop et al, 2014, p. 1208).

Esbensen & Seltzer (2009) focused on the progress of RRBs and they suggested that RRBs decrease over time. The researchers used the Repetitive Behaviour Scale-Revised (RBS-R; Bodfish et al, 2000), a caregiver-report measure that focuses only on RRBs, to assess the progress of these behaviours over time. Their sample consisted of combining data from many studies of RRBs (n=712) in individuals with ASD, aged 2-62 years old. However the results are limited by the fact that the analysis was based on modified cross-sectional data.

Similarly to Esbensen & Seltzer (2009), Joseph et al (2013) also used the RBS-R to assess the RRBs in their sample. Their participants were 277 children (aged 2-11 years old); more specifically 128 children with autism, 46 with PDD-NOS, 44 with non-spectrum developmental delays and 59 typically developing children were

followed for two years. Based on their findings the RRBs of children with autism did not decrease. Moreover, the RRBs were found to be stable over time in children with autism between the ages of two and seven years. Also, Joseph et al (2013) found that the amount and type of RRBs varied based on diagnosis and that there was not a significant correlation between RRBs and age, cognitive functioning, sex or social communication impairments.

Militerni et al (2002) conducted a cross-sectional cohort study of a group of children aged 2-4 years old and another group aged 7-11 years. Parental report data and observation during play were used to assess the children and based on the results the younger group presented with more recurrent motor and sensory restricted and repetitive behaviours. Richler et al (2010) used the ADI-R to assess the progress of these behaviours on children with autism and children with non-spectrum developmental delays over 9 years and they found that the repetitive sensory motor behaviours did not decrease over time.

Likewise, Constantino et al (2009) explored the progress of social impairment in children with autism from 3-18 years of age and reported stability of symptoms with a hint of improvement. Honey et al (2008) recruited 104 children (aged 24-48 months) with autism, autism spectrum disorder or other disorders and followed them for 13 months. The researchers used relevant items from the ADI-R and their findings were consistent with prior research by Joseph et al (2013) since they found that the children's ability level might relate to the level of repetitive behaviours, with higher-level repetitive behaviours developing in children with lower adaptive functioning and language skills. Compared to the findings by Joseph et al (2013), in the Honey et al (2008) study RRB scores increased over one year but across time they decreased. In addition, it was suggested that the RRBs remained but their impact decreased.

However, the effect of the speech and language therapy the children received and the fact that there was not enough information provided relative to the other interventions the children had during the study, might have influenced the results.

Harrop et al (2014) carried out a short-term longitudinal study (3 time points within 13 months) in order to explore the trajectory of restricted and repetitive behaviours of children with autism. Similarly to Militerni et al (2002) the authors used observation methods during free play with the primary caregiver to assess lower-order restricted and repetitive behaviours in children with autism aged 2-5 years old in the beginning of the study and compared them to a group of typically developing children of the same age. Based on the findings the group of children with autism demonstrated more frequent RRBs. However, these behaviours were also present in the other group but limited to just one form: "fiddles with objects/uses objects in repetitive and non-functional manner" (Harrop et al, 2014;p. 1215). In addition, the RRBs in the autism group remained constant during the 13 months of the study. These findings are consistent with Honey et al (2008) and Richler et al (2010). Nonetheless, it should be taken into consideration that 13 months might not be enough time for children with autism to change significantly.

Harrop et al (2014) also reported that the children in the autism group who had lower non-verbal ability and language demonstrated more frequent RRBs, and this was also seen in the Militerni et al (2002) and Szatmari et al (2006) studies, but a relationship between the frequency of RRBs and social communication was not found. As the authors also note, with respect to the limitations of the study, the observational methodology might have limited the validity of the results but the positive link found between the ADOS scores for RRBs and the frequency of observed RRBs offers some validation for the methods. Nonetheless this link was

demonstrated at all three points of observation and the correlations were low. Furthermore, it should be noted that the coders were not blind to the aims of the study or the group distribution and the researchers did not control for the language variable in the group analysis and they did not recruit language matched typically developing controls.

Fecteau et al (2003) reached similar results as seen earlier in the Constantino et al (2009) study. Fecteau et al (2003) identified better progress in social and communication skills than in RRBs in a sample of 28 verbal children and adolescents with ASD. In their study the developmental changes were assessed by the ADI-R and the authors compared the symptoms of autism identified using a retrospective assessment for the 4-5-age period.

Moore and Goodson (2003) carried out a study following 20 children with autism at two time points, when they were two years old and when they were four years old. The authors also used the ADI-R to assess the children's restricted and repetitive behaviours and interests and contradicted previous findings by Richler et al (2010) since they found that the specific behaviours were reduced over time but became cognitively more complex. In addition it was found that their diagnosis remained. However, the use of ADI-R in all of the studies above might have affected the results since it is a parent-report measure.

Table 10. Restricted and Repetitive Behaviours and interests (RRBs) over time

Study	Country	Sample	Assessment Measures	Key findings
Esbensen et al (2009) Cross-sectional	USA	Combined data from many studies of RRBs (n=712) in individuals with ASD, aged 2-62 y	RBS-R	- Autism symptoms lessen with age
Szatmari et al (2006) Factor analytic	Canada	339 children with PDD (mean age 100.79 m)	ADOS, ADI-R, Leiter ,VABS	- Higher levels of repetitive sensory motor behaviours were associated with lower functioning
Joseph et al (2013) Cross-sectional and Longitudinal	USA	128 children with autism, 46 with PDD-NOS, 44 with non-spectrum developmental delays and 59 typically developing children (aged 2-11 y)	RBS-R, ADOS, ADI-R, MLES, DAS-II	- Stability in RRBs of children with autism aged 2-7 y - No significant correlation between RRBs and age, cognitive functioning, sex or social communication impairments
Richler et al (2010) Longitudinal	USA	192 children under the age of 3 y referred for evaluation for possible autism and 22 children of the same age with non-spectrum developmental disorders	MSEL, MPR, WISC-III, DAS, ADOS, ADI-R	- Repetitive sensory motor behaviours did not decrease over time
Constantino et al (2009) Prospective	USA	95 male–male twin pairs aged 8 - 15y, 95 children with Pervasive Developmental Disorders	SRS, DIGS/FIGS	- Subtle improvement of autistic social impairments over time - Biggest improvements noticed over time in those most affected by autistic social impairments at the start of the study

Militerni et al (2002) Cross-sectional Cohort	Italy	121 children with autism in 2 groups: 75 toddlers (mean age 3.4 y) and 46 children (mean age 8.9 y).	WISC-III, GMDS, WISC, a semi structured questionnaire was developed from a number of existing instruments, such as the Y-BOCS, the CARS , the ABC , and the SBS	- The younger group presented with more recurrent motor and sensory restricted and repetitive behaviours - Older children had more complex behaviours.
Honey et al (2008) Longitudinal	UK	104 children (aged 24-48 mo) with autism, autism spectrum disorder or other disorders	ADI-R, ADOS, MSEL,VABS	- RRBs remained but their impact decreased - RRB scores increased over one year but across time they decreased
Harrop et al (2014) Longitudinal	USA	1) Children with autism (n = 49; mean age 45 mo) 2) Children with typical development (n = 44;mean age 24 mo)	ADOS, ADI-R, MSEL, PLS, RBQ-R, DISCO, items from the Direct observation of repetitive behaviours in autism and the coding scheme of Barber et al. (2012) and Watt et al. (2008)	- The group of children with autism demonstrated more frequent RRBs - The RRBs in the autism group remained constant during the 13 months of the study
Fecteau et al (2003) Retrospective	Canada	28 verbal children and adolescents with ASD (mean age: 13y)	ADI-R, ADOS, WISC–III, WISC–R, WAIS–R	- Significant improvements in all domains - Fewest improvements in restricted interest and repetitive behaviour domain
Moore and Goodson (2003) Longitudinal	UK	20 two-year old children with autism	ADI-R	- Diagnosis of autistic spectrum remained stable over time - Communication and social skills of the children showed little change overall at follow-up

2.6 Development of Language

The start and development of language is a process that can be affected by several factors, like the interaction of a child and their environment (Iverson, 2010). Joint attention is defined as the ability of a child to coordinate their attention between a feature in their environment and a social partner (Malesa et al, 2013). The association between joint attention and later language development might be attributed to the communicative function of joint attention (Malesa et al, 2013).

Pickles et al (2014) assessed the development of expressive and receptive language of children with autism in the USA. The participants were 192 children who were referred for autism and a battery of diagnostic and psychometric instruments were utilized to assess them on six occasions between ages 2 and 19 years old. Seven subgroups, each subgroup differing on the level of language ability were identified via multivariate latent growth curve analysis and the results highlighted the relative stability of language development in autism beyond six years. More specifically, it was found that beyond the age of 6 children progressed in a similar manner but before the age of 6 there was a variation in their progress. The results might reflect the plasticity that defines early childhood. Thus, different environments can be more or less advantageous for children to learn language. Also, as it is noted by Pickles et al (2014) the uniform progress of the children's language beyond age 6 could be a result of the intensive treatment they received, but intervention context was not explored in detail.

Wetherby et al (2007) explored the social communication skills of children with autism in the USA and found that language comprehension at 18- to 24-months of age was the best predictor of developmental outcome (both verbal and nonverbal) at 3 years for children with autism. Similarly, Thurm et al (2007) found that

nonverbal ability in 2-year-old children with autism in the USA was the strongest predictor of developing functional language at age 5, suggesting that there is a strong link between cognitive ability and language outcomes.

Weismer & Kover (2015) explored language development in 129 children with ASD in the USA in four assessments (2½-5½) and a prospective longitudinal design was used. The ADOS calibrated severity scores (CSS) were used to measure the role of autism symptom severity relative to cognition and other factors that might have affected the development of language. In addition standardized tests were used to obtain measures of several domains of the children's development along with parent questionnaires. As it is stated by Weismer and Kover (2015) joint attention did not predict the rate of language change, which was also reported in the Toth et al (2006) study who found no association between joint attention and communication development across the preschool and early-school age period. Nonetheless, a number of children who did not show evidence of response to joint attention when they were 2½ appeared to have low verbal skills at age 5½ in the Weismer and Kover (2015) study. Joint attention has been found to be a predictor of language development in several studies (Gillepsie-Lynch et al, 2012,2015; Gulsrud et al, 2014; Malesa et al, 2013; McDuffie et al, 2005; Siller & Sigman, 2008; Sullivan et al, 2007 and Whalen et al, 2006;).

Barbaro (2012) suggested that it is necessary to map the early development of verbal and non-verbal skills in order to comprehend better the development of children with autism throughout the years and to understand how it differs from typical development. Based on Anderson et al (2014) the strongest predictor of more positive development of children with autism is fast increase of their verbal IQ between ages two and three.

Rutherford et al (2007) conducted a longitudinal study in the USA to further our understanding of the development of pretend play in children with autism over time. The participants were twenty-eight children with autism (average age-33.9 mo), eighteen with other developmental disorders (average age-34.8 mo) and twenty-seven typically developing children (average age-19.5 mo) matched on overall mental age at both time points. The children in the first two groups were assessed twice over a 24-month period and the rest were seen twice within a 12-month period, because they wanted to preserve developmental matching. Results indicate that at the initial assessment the autism group presented with impairments in all kinds of play (pretend and sensorimotor), but at time 2 deficits were found only in their pretend play and not in sensorimotor play. Additionally, it was reported that the group with the developmental disorders did not differ from the control group with respect to pretend play and joint attention predicted pretend play development roughly equally in all groups.

Haebig et al (2013) explored the longitudinal links between two categories of parent verbal responsiveness and language comprehension and production one year later in forty toddlers and pre-schoolers in the USA that were diagnosed with autism. The responsiveness of the parents was coded from videotapes of parent-child play that were collected at time 1, which was the initial annual visit of a larger study. Parents and children were then reassessed twelve months later. It is noteworthy that in this study one of the findings suggested that the relationship between parent linguistic input and later language achievements may vary based on the child's stage of language development. In addition, results showed that children with autism who are verbally fluent might require more advanced language input in order to achieve further development of their language. On the other hand, a positive association

between parent follow-in comments and later language development in the group with minimal expressive language was found. This finding also adds support to the results of Siller & Sigman (2002; 2008).

Siller & Sigman (2002) were the first to show that responsiveness in parents of children with autism in the USA contributes to later development in language. In a subsequent study, Siller & Sigman (2008) conducted another study in the USA aiming to replicate and extend their previous findings about the association between parents' responsiveness and language development. Twenty eight children with autism were included in this study and the findings contribute to the previous ones as they showed that the children's degree of language growth was independently predicted by the level of parents' responsiveness to their children's attention and activity during play and by children's responsiveness to other's suggestion for joint attention. Thus, it was found that preschool children with autism who responded more to joint attention tasks obtained language faster than the ones that did not respond as well. Although the findings of this study are important it should be taken into account that if the sample was more homogeneous in regards to the chronological age of children at study entry and if there were more participants it would allow us to generalize the results to all children with autism more confidently.

McDuffie et al (2005) investigated predictors of vocabulary comprehension and production in a group of children with autism in the USA. In accordance with the findings by Sullivan et al (2007) it was found that greater occurrences of joint attention predicted later vocabulary acquisition, as well as comprehension and production of novel words.

The results of the Gillepsie-Lynch et al (2012) study were consistent with the findings of the Siller & Sigman (2002; 2008) studies. Gillepsie-Lynch et al (2012)

evaluated twenty participants in the USA between early childhood (M=3.9 years) and adulthood (M=26.6 years). Responsiveness to joint attention (RJA), language and Developmental Intelligence Quotient (DQ) were assessed in early childhood. In adulthood, the parents of the participants were interviewed and adaptive functioning, autistic symptomology and global functioning were assessed. Gillepsie-Lynch et al (2012) looked into various correlations between measures and highlighted the importance of joint attention for developing social skills. The results showed that better RJA and language ability at 4 years are linked with a higher level of functioning in adulthood. RJA was also predictive of language ability at 27 years. Furthermore, a correlation was detected between improvements in language ability and Developmental Intelligence Quotient (DQ) between 4 and 18 years and adult outcomes.

Table 11. Development of Language

Study	Country	Sample	Assessment Measures	Key findings
Pickles et al (2014) Longitudinal	USA	192 children referred for autism assessed between 2 and 19 y	ADOS, ADI-R, VABS, MSEL, parent interviews and diaries	- Beyond the age of 6 children progressed in a similar manner - Before the age of 6 there was a variation in their progress
Thurm et al (2007) Longitudinal	USA	110 children referred for possible autism and 21 with developmental delays and no evidence of autism followed from 2-5 y	ADI-R, PL-ADOS, SICD, DAS,VABS, MSEL	- Nonverbal ability in 2-year-old children with autism was the strongest predictor of developing functional language at age 5
Weismer & Kover (2015) Prospective longitudinal	USA	129 children with ASD were assessed from age 2½ to 5½	ADOS, CSS, ADI-R, PLS-4, PPVT-4, Bayley-III, VABS-II, ESCS	- Joint attention did not predict the rate of language development - ASD severity predicted growth in language comprehension and production - Cognition predicted growth in production
Wetherby et al (2007) Prospective Longitudinal	USA	50 children with ASD (average age:21,36mo), 23 with developmental delays (20,71 mo) and 50 with typical development (21,14 mo)	ADOS, VABS, MSEL, SCQ, CBS	- Language comprehension at 18- to 24-months of age was the best predictor of developmental outcome (both verbal and nonverbal) at 3 years for children with autism

Barbaro (2012) Prospective Longitudinal	Australia	109 children with ASD;8 children assessed at 12-, 18-, and 24-m, 29 children were assessed at 18- and 24-months, and 72 children assessed at only one time point (2 at 12-months, 8 at 18-months, 62 at 24-months)	ADOS, ADI-R, MSEL	- Developmental slowing in the 2nd year of life of children with autism - Poor Receptive relative to Expressive Language skills appears very early in life for children on the spectrum
Rutherford et al (2007) Logitudinal	USA	28 children with autism (mean CA: 4 y and 3mo), 18 children with other developmental disorders (mean CA: 4y) and 27 typically developing children (mean CA: 2y and 6mo)	ADOS, ADI-R, ESCS, MSEL, Fewell Play Scale, 5th ed.	- Joint attention predicted pretend play development roughly equally in all groups
Siller & Sigman (2002) Prospective longitudinal	USA	25children with autism, 18 children with developmental delay, 18 typically developing children	ESCS, Cattell Infant Intelligence Scale, RDLS, CELF-R, CELF- P, MSEL, video observation of child-caregiver interactions	- Caregivers of children with autism who showed higher parental sensitivity had children who developed superior joint attention and language over a period of 1, 10, and 16 years than did children of caregivers who showed lower levels
Haebig et al (2013) Longitudinal	USA	34 parent–child dyads evaluated annually at time 1 (mean age : 31.35 mo) and time 4 (mean age = 66.91 mo)	ADOS, ADI-R, PLS-4, video observation of parent-child play sessions	- Relationship between parent linguistic input and later language achievements may vary based on the child's stage of language development - Positive link between parent follow-in comments and later language development in those with minimal expressive language

McDuffie et al (2005) Longitudinal	USA	29 2- and 3-year-olds diagnosed with autism spectrum disorders (mean age: 32 mo) were assessed at entry and 6 mo later	PAF, MIS, STAT, CDI, video observation of intentional communication	- Greater occurrences of joint attention predicted later vocabulary acquisition, as well as comprehension and production of novel words
Siller & Sigman (2008) Longitudinal	USA	28 children with autism were assessed during early and middle childhood	MSEL, RDLS, CELF-R, ESCS, video observations of maternal indicating behaviours, maternal verbal behaviours, and children's toy-directed attention.	- Preschool children with autism who responded more to joint attention tasks obtained language faster than the ones that did not respond as well - Children's degree of language growth was independently predicted by the level of parents' responsiveness to their children's attention and activity during play
Gillepsie-Lynch et al (2012) Longitudinal	USA	20 participants between early childhood (M=3.9 y) and adulthood (M=26.6 y)	ESCS, Cattell Scales of Development, Stanford-Binet 4th ed., MSEL, RDLS, CELF-R, ADI-, VABS, overall social functioning questionnaire	- Change in adaptive behaviours with development, but not in symptoms of autism
Whalen et al (2006) Longitudinal	USA	10 children with autism (mean age: 4y 2 m)	Unstructured Joint Attention Assessment, Structured Joint Attention Assessment, Empathic Response assessment, Structured Play Assessment	- Teaching joint attention skills contributed to the increase of spontaneous speech - Small decrease in the frequency of spontaneous speech

2.7 Summary

Many studies reviewed here included a large number of participants, assessed their sample longitudinally and reported positive change in the development of children with autism over time.

Overall, existing research appears to suggest some stability of symptoms in autism over time, with some suggestions that certain skills are more prone to fluctuate. Research suggests that the changes seen in autism symptoms vary across a number of different areas. For example, Baghdadli et al (2006) reported developmental regression in the daily living skills and person-related cognition of children with autism but stability in other areas like: communication, socialization and object-related cognition. Gotham et al (2012) suggested that some children with autism (e.g. children with high verbal IQ and adaptive behaviour) could improve over time with respect to their symptoms while others might demonstrate regression. However, Sutera et al (2007); Kelley et al (2010) and Werner et al (2005) reported stability of autism symptoms over time. Differing results may be in part due to methodological differences across studies and to a lack of measurement of important aspects such as intervention context.

With respect to predictors of outcome most of the research suggests that high cognitive skills in the early years of the child are linked with more advanced development of children with autism and in decreases in autism symptoms severity over time (e.g. Turner & Stone, 2007). Another key finding was the decrease or stability of the Restricted and Repetitive Behaviours and interests of children with autism over the course of years. Furthermore, significant heterogeneity was reported in most of the studies that focused on the trajectory of autism symptom severity.

Turning to the studies that looked into the development of children with

autism from childhood to adolescence and adulthood, it appears that an overall improvement in individuals with ASD over time and a decrease in their autism symptoms were mostly reported. In light of previous findings (Anderson et al, 2009) most of the research that followed up individuals with autism during adolescence and adulthood also suggested a link between lower cognitive skills and fewer improvements. Research suggests that another factor that might influence the development of individuals with ASD is the behaviour of their parents (see section 2.4).

Moreover, most of the studies reviewed in section 2.6 suggest that early joint attention skills are vital to subsequent development of children with autism in several domains. On the whole these findings suggest that joint attention is an important aspect to consider, especially in relation to later language development. For example, McDuffie and colleagues (2005) found that greater occurrences of joint attention predicted later vocabulary acquisition, as well as comprehension and production of novel words.

2.8 Conclusions

Autism Spectrum Disorders were mostly explored in early childhood but recently there is a shift in the interest and the attention has turned into the progress of different components of the disorder across the life span. Most of the studies reviewed here tend to focus on preschool children and this could be related to the special interest of researchers in early intervention and in the way this could affect the course of autism. Research suggests that early social and communication functioning in autism affects the initial diagnosis (Charman et al, 2005; Lord et al, 1989). Therefore,

it is considered important to study the development of these aspects of the disorder from early on.

In the body of research reported above the longitudinal design was mostly used in order to observe the development of children with autism recurrently over a period of time. This period of time varies based on the research and the participants are usually cohort. There are several strengths and weaknesses associated with this type of design.

Longitudinal research measures prevalence at several points in time, and can provide information on causation, prognosis, stability, and change (Rutter, 1988, cited in Sanson et al., 2002). However, the generalizability of the results in a longitudinal study could be limited since all participants are from one cohort and the findings usually refer to one generation. The size of the cohort though is important when considering the validity of the findings of a study. Another disadvantage is that when children are studied over a long period of time, researchers might become more subjective. Also, in this case the participants may become familiar with the content of the assessments and the improvements in their performance may not mirror the reality of their development. Finally, another factor that weakens the results in most of the studies included in this chapter is that there was not enough information provided about the effect the different treatments the participants used might have on their development over time. Additionally, the use of observational methods in the majority of the studies might have also affected the validity of the results.

The findings of the studies reviewed here underline the importance of early identification and intervention, and contribute to the greater effort to increase public awareness of the early signs of autism. More longitudinal research is needed in which

children with early and later manifestation of autism are followed and there is also a need for more research on the long-term effects of different therapy contexts.

Research (Bagdhadli et al, 2013) suggests that the time of entry into therapy, the intensity of the intervention and its duration along with its components are critical for the development of children with autism. Therefore, it is important to further explore these features and determine how they affect individuals with autism over time. Also, there is a growing need to explore the variables that are used as predictors of outcome for pre-schoolers with autism. It is worth mentioning that there is very little research related to the progress of individuals with autism as they move from childhood and adolescence into adulthood. Longer follow-up studies could help find predictive factors across the life course in order to gain a better understanding of autism. Studies that focus on the trajectory of autism help identify specific factors linked with distinct trajectories and lead to a better understanding of the functional areas that need to be targeted by each intervention. In order to predict future behaviour it is important to investigate how autism symptoms manifest over time.

Chapter 3 Health care context

In this study we engage with the question of whether autism manifests differently across Greece and the UK. In order to move towards a better understanding of the development of children with autism across these two countries, a review of the healthcare context of both countries is required. Additionally, it is important to comprehend how autism is treated in each country and how parents experience the whole process of diagnosis, treatment and support.

In section 3.1 the healthcare provision in Europe is discussed to provide the wider context of the study and sections 3.2 and 3.3 provide an overview of the healthcare systems in the UK and Greece. Sections 3.4 and 3.5 assess the mental health care provision for children across the two countries and particularly the service provision for children with autism and discuss the special education needs sector, issues of stigma and parents' experiences of children with autism. In conclusion to this chapter, in section 3.6 the similarities and differences in health care provision for children with autism and their families between the UK and Greece are highlighted.

3.1 Health care provision in Europe

A definition of a health system is provided by the World Health Organization (WHO, 2000) who state that a national health system comprises of ''all activities whose primary purpose is to restore and maintain health . . . improving the health of the population they serve, responding to people's expectations, and providing financial protection against the costs of ill-health'' (WHO, 2000: 5–8). All countries in Europe have some form of a healthcare system but they differ in the way they function and are funded (Goodwin, 2008).

For centuries in many European countries, religious orders provided a form of

hospital care (Freeman, 2000). Health care was also sometimes offered publicly by local parish and municipal governments (Freeman, 2000). Between 1750 and the mid-nineteenth century Europe was characterized by innovative industrial, social, and political developments, and the impact this had on society led to the Industrial Revolution.

The 19th century was a period when various public health movements arose among different European countries aiming to improve sanitation and this period was also characterized by the rapid growth of hospitals. For example, hospitals were established in Britain, as the result of voluntary efforts by private citizens (Warren, 2000). In addition, at that time there were efforts to educate people in health matters and in 1852 Sir John Pringle published a book that discussed ventilation in barracks and the provision of latrines. However, as the Industrial Revolution expanded across different parts of Europe, the health and welfare of the workers deteriorated due to poor employment, housing and living conditions. As a result there were outbreaks of epidemics such as influenza, typhus, typhoid, cholera and smallpox. This situation led to a movement towards reforms in order to improve sanitation and a number of international sanitary conferences took place, which led to the establishment of other public health initiatives such as the provision of clean water and improved sewerage provision (Keller, 2010). The establishment of these institutions led to the development of international health organizations, including: the Office International d'Hygiène Publique (1907); the League of Nations Health Organization (1920); and the World Health Organization (1948) (Keller, 2010).

The timing that national health services (NHS) were established in Europe has varied considerably. Germany was the first to introduce a public, compulsory system of health insurance for industrial workers in 1883 (Freeman, 2000). Health care in the

UK has been influenced by a variety of reforms beginning with the New Poor Law of 1834 and a publicly funded NHS was established in 1948 (Freeman, 2000). However, for other countries in Europe the establishment of national health services came much later. A reconstruction of health services in Portugal began after the revolution of 1974, which led to the establishment of the NHS in 1979 (Barros et al, 2011). The NHS in Italy was established in 1978 (Donatini et al, 2001) and in Spain the NHS was developed after the Health Care General Act in 1986 by the first socialist party government of the restored democracy (Garcia-Arnesto et al, 2010). It was not until 1983 that the National Health System in Greece was established when the socialist party came to power (Ballas, 2004).

During the twentieth century, the state increasingly became politically responsible for health provision across Europe (Maarse, 2006,). However, after the long post-war boom in the 1970s all European countries faced various challenges with respect to health care. More specifically, they found it difficult to satisfy the rising health care costs for different reasons, such as: international economic recession and ascending unemployment; improvements in healthcare technology and treatments; growing health care demands due to an ageing population. All this contributed to the elimination of the GDP (Gross Domestic Product) and a large part of public budgets having to be spent on health care (Andre & Hermann, 2008). Since the international economic recession in the 1970s all European countries have faced similar difficulties in covering the increased health care costs, with forms of economic austerity introduced in many countries (Andre & Hermann, 2008).

The financial and economic crisis between 2008 and 2009 affected almost all European countries. According to Garel and Lombardi (2011) in many countries in Europe, such as the UK, Spain, Portugal, Greece, France, wages were reduced and

unemployment increased. Consequently, the resources produced by taxes and social insurance contributions were lowered and this affected the health system's capacity and sustainability. This financial crisis has changed the function of different features of the health systems in Europe, with a number of recession measures taken with respect to health policy (European Hospital and Healthcare Federation, 2011). In countries where national austerity measures have included significant cuts in the health system accompanied by general tax increases, it has become more and more difficult to support the health system (Clemens et al, 2014). This is the situation experienced recently in Greece, that will be discussed later in this chapter.

It is of interest to look into the mental health care provision as well, since autism service provision is integrated in the mental health sector in most European countries (Braddick et al, 2009). Regarding mental health care provision in Europe, during the last 30 years there has been a movement across many European countries to transform their mental health policies in order to provide better care and support to their communities, instead of institutional care. Throughout the 1990s and early 2000s the Mental Health Declaration for Europe and the Mental Health Action Plan for Europe were introduced and they are considered the most significant steps towards the reform of the mental health system in Europe (Semrau et al, 2011). This reorganization mirrors the recognition of the growing need to change the mental health systems that included old-fashioned and remote institutions, such as asylums (Balan and Pauna, 2014). Since then mental health has been acknowledged as a priority and most European countries have committed to the development of community-based mental health services and their integration into primary health care aiming to lessen the stigma associated to mental illness and other disabilities (Semrau et al, 2011). However, the specific aims and political context vary among the different

countries in Europe. With the economic austerity across Europe there is general concern about the outcomes and the quality of services provided to the general population and especially for children and their families.

As stated in the "State of Mental Health in the European Union" report (2004), each Member State of the European Union is responsible for the organization of their own mental health care system in which a range of services are co-ordinated. It is also mentioned in the report that in most European countries during the last years there has been a reform in their mental health care system and some of them had been through similar developments years earlier. The "State of Mental Health in the European Union" report (2004) suggested that mental health is mostly incorporated in general health care and the national or regional government is responsible for this sector in most European countries. Outpatient care is largely provided in Europe in either hospitals or mental health centres where teams of specialists and psychiatrists reside. Additionally in the countries where general practitioners play the role of the gate keeper in health care, people are usually referred by GPs except in case of an emergency. The promotion of mental health and programmes aiming to combat mental illness stigmatization may vary across countries (European Commission, 2004). Nonetheless, several projects have been funded by the European Commission since 2003 in order to promote mental health across Europe (Knapp et al, 2007). As mentioned by Jane-Llopis et al (2006) non-governmental organizations (NGOs) also play an important role in mental health promotion and prevention of mental illness in Europe.

Children's health services can have complex needs ranging from interventions to improve mental health, such as anti-bullying and emotional literacy projects to specialized intensive care (Lenton, 2014). Berra et al (2009) carried out a comparative

study in Europe and noted that in countries with a higher per cent of public health expenditure children and adolescents tended to use more often the health care services. In regards to child and adolescent metal health services in Europe, these are separated and run by different staff that cooperate with other child agencies and schools. In most European countries there are: child and adolescent psychiatrist/psychologists/psychotherapists in private practice, outpatient departments in hospitals, child psychiatric services at public health agencies, child guidance clinics, family counselling services, early intervention centres and social paediatric services (Remschmidt & Belfer, 2005).

As it is stated in the "Child and Adolescent Mental Health in Enlarged EU: Development of Effective Policies and Practices" (CAMHEE, Braddick et al, 2009) there is a lack of awareness and knowledge with respect to different methods in order to promote child mental health and reduce mental illness. The CAMHEE programme (2007) started in January 2007 and aimed to provide recommendations and guidelines for effective child and adolescent mental health policies and practice across Europe. It is also important to consider that during the last years in many European countries there is a shift from institutional to community care services for children and from inpatient to outpatient therapy (Braddick et al, 2009).

3.1.1 Summary

The development of health systems in Europe has varied across countries. It was not until the 1980s that almost all European states guaranteed access to health care to almost all of their citizens but the timing that national health services have developed has varied between different countries across Europe. Since the

international financial crisis of 2008, Europe has experienced economic recession that has led to deficits in public budgets. Thus most healthcare systems in Europe are challenged by similar difficulties because of the financial austerity and there is a concern about the outcomes and the quality of mental health services especially those provided to children and their families.

3.1.2 Different models of health care provision

The European health care system can be divided into two basic healthcare models: the Bismarckian model and the Beveridgian model. The Bismarckian model was established in the end of the 19th century by Bismarck in the newly unified Germany. This model is mostly based on social health insurance for wage-earners. This insurance system is mainly financed collectively by employers and employees via payroll deduction (Minor, 2010). Germany, France and Austria are some of the countries that use the Bismarckian model. The Beveridgian model was established in 1948 by Beveridge in the UK. In this model, health care is provided and financed by the government through tax payments and a national health service provides health care services to the general population (Saltman and Dubois, 2004). Other countries that use this model include: Greece, Spain, Italy, Sweden and Portugal.

According to Mladovsky et al (2009) most European Countries aim to reduce inequalities in health care and make sure that health services are distributed equally. An equitable healthcare system aims for all citizens to have access to appropriate care and avoid a system that leads to some individuals being able to access only the minimum level of care (UCL, 2012). However, in some countries access to healthcare might be more difficult for lower income individuals, due to the existence of out of pocket payments. These can include direct payments from a patient for services or

goods, such as prescription pharmaceuticals or x-rays. In countries such as Greece, Cyprus and Bulgaria these kinds of payments comprise over 40% of all health costs (Mladovsky et al, 2009).

3.1.3 Public vs Private healthcare provision

As discussed in the previous section, healthcare in Europe is funded either through taxation or social health insurance. Thus, public funding is the main source of funding for health care spending in most European countries. However, this does not mean that the public sector is solely responsible for providing health care and throughout Europe there is a mix of public and private healthcare provision.

Private healthcare provides an alternative choice to patients who do not wish to use publicly provided health care such as the NHS. In the private sector there are private for-profit and not-for profit organizations. Also, health insurance can be paid by someone's employer or for others it can be paid individually (Andre & Hermann, 2008).

According to Freeman (2000), the relationship between public and private health care is associated with the tension between political control and professional autonomy. Also, the link between private and public health care can be conceived as an issue of ethics or of economics, since the fact that private medicine exists could imply that sometimes access to healthcare is associated with the ability to pay. However, countries with NHS systems do not often fit this ideal one-model description as they have private health care provision as well, such as private hospitals and doctors that work in the NHS and privately (Rothgang, 2008).

In countries with Social Health Insurance systems (e.g. Austria, Belgium, France, Germany) inpatient care mainly relies on public or private non-for- profit

hospitals (Eeckloo et al, 2007). Privatization in these countries is mainly driven by permanent fiscal austerity and perceived deficits in the inpatient sector (Schmidt, 2010). Moreover, implicit privatization occurs in order to change from inpatient to outpatient care that can be considered as an effective method of cost containment. For example, this shift has been taking place in France since the 1980s (Schmidt, 2010).

According to Maarse (2006), privatization seems to be encouraged when the public health system is perceived to be failing. Then, people become more eager to turn to a private setting and avoid the perceived lower quality care and long waiting times that they expect to find in the public sector. Also, affluence has been linked with privatization with affluent people often paying for private services and for what is considered a better quality of healthcare (Maarse, 2006).

Galetto et al (2014) have noted that there is a recent trend in Europe towards making the public sector more similar to the private one, for example by offering people the choice of which hospital to attend for treatment. As it is suggested by Andritsos and Tang (2014) the existence of private care can also benefit those people who need urgent care or have a severe condition, as it reduces the number of patients that need to be treated publicly and directs the demand accordingly. Indeed Olivella (2003) has suggested that private health care contributes to the reduction of longer waiting lists in the public sector.

3.1.4 Summary

A mix of public and private healthcare is present across Europe. In many countries with National Health Systems private healthcare exists along side the public provision. It could be argued that a mix of private care in a public system provides greater choice to the general public. The tension between political control and

professional autonomy can be linked with the relationship between public and private in healthcare and the link between them could be considered as an issue of ethics or of economics (Freeman, 2000).

3.2 The National Health System of the UK

When examining the National health system of the UK it is essential to include a brief overview of its history. Hospitals in Britain came into existence during the medieval times when the church took responsibility for health care provision. The oldest hospital in London is St. Bartholomew's that was founded in 1123 by Rahere, a favourite courtier of King Henry I (Waddington, 2003). During the thirteenth century there was an increase in the establishment of hospitals and in the fourteenth and fifteenth centuries university graduates who also held positions in the church often played the role of physicians (Ham, 2009). Throughout the sixteenth century the scientific method spread and by its end medical knowledge expanded. At that time, a group of specialists known as "barber-surgeons" emerged in Britain. These were medical practitioners that performed surgery. Doctors, who had formal institutional training, were more expensive than barber-surgeons and they considered surgery as an inferior task. In Renaissance England there were three types of medical practitioners: physicians, surgeons and apothecaries (Ham, 2009).

As Ham (2009) describes by the nineteenth century voluntary hospitals along with municipal hospitals were responsible for the healthcare provision. Doctors offered ambulatory care in the community and there was no centrally organized state health care system. However, various central and local boards were established in order to deal with public health and sanitation issues. In the late nineteenth and early twentieth century, the Labour Party was established and this increased the political

pressure to offer more help to people in regards to health care. A compulsory national health insurance scheme was introduced in the 1911 National Insurance Act by the Liberal Government of 1906-1914. By the end of the 1930s there were two hospital systems in the UK: the public sector and the voluntary hospitals. Based on developments that occurred during the Second World War and more specifically, the Beveridge Report (Beveridge, 1942), the Labour Government put in motion the National Health Service Act in 1946. The main objective of this historical legislation was to make health services free at the point of delivery (Boyle, 2011).

The establishment of the National Health Service was on 5 July 1948 and the aim was to provide health services for all. Aneurin Bevan, the Minister of Health at that time, is considered to be the founder of NHS. After 1948, a salaried service was initiated for hospital doctors and the hospital outpatient service was further developed (Ham, 2009).

The 1950s were considered to be the years of "make do and mend" (Ham, 2009, p.17) in the hospital service, as capital expenditure during the decade was equivalent to 100 million pounds. As a result, no new hospitals could be built. However, the situation changed with the 1962 Hospital Plan, which provided for an expenditure of 500 million pounds in England and Wales in the ten years up to 1971 (Rivett, 1998). Twenty years after the development of the NHS, significant developments occurred relating to the British Medical Association's Charter for the Family Doctor Service published in 1965, which led to a new contract for GPs. This contributed to the expansion of health centres and the emergence of primary health care teams (Ham, 2009).

In 1974 the NHS was reorganized as fourteen Regional Health Authorities, covering all three parts of the NHS and incorporating the teaching hospitals. A new

level of Area Health Authorities was established, with boundaries mostly adjacent to local authorities, along with the regions and the district health authorities that managed the hospitals (Rivett, 1998). During the first half of the 1980s the government was interested in making the NHS more business-like and efficient. The Griffith's Report of 1983 (Evans, 1984) played an important role in changing the management structure of the NHS with general managers introduced at all levels in NHS.

The White Paper in 1987 laid out the Conservatives' goals for a new contract for GPs. During 1991-1997, a period of limited growth, an "internal market" was introduced throughout the UK, changing health authorities' responsibilities by separating the roles of purchaser and provider (Bevan, 2011). The NHS experienced a significant change, outlined in the 1989 White Paper (Department of Health, 1989), Working for Patients which passed into law as the NHS and Community Care Act 1990 (Department of Health, 1990). The internal market was the Conservative Government's attempt to address problems, such as growing waiting lists.

In order to better understand the health care provision in the UK since the 1990s it is important to clarify that it now consists of four separate countries (England, Scotland, Northern Ireland and Wales). Separate administrations have been elected in Northern Ireland, Scotland and Wales and these are now responsible for health and social care. In England between 2006 and 2013 health care was organised and provided locally through 152 Primary Care Trusts (PCTs) that are responsible for the health care provision of people in a specific geographical area (Legido-Quigley et al, 2008). The PCTs provide primary, secondary (hospital) and community services that are purchased from mainly the NHS but also private and voluntary organisations

and also co-ordinated with one or more local government bodies providing social care (Legido-Quigley et al, 2008).

In recent years there has been a greater move towards the provision of primary health care in England, with GPs (General Practitioners) playing an increasingly central role for primary care services and commissioning. This includes provision by other health care professionals and organizations that function as part of the general practice system, such as walk-in-centres, NHS Direct, and community health service providers. The role of GPs is also relevant to this study as it is usually GPs that refer children to the Child and Adolescent Mental Health Services (Vallance et al, 2015). Also it is the Primary Mental Health Workers (nurses/social workers/psychologists) who liaise between primary and specialist child and adolescent mental health services (Macdonald et al, 2004).

With the implementation of the Health and Social Care Act (Department of Health, 2012) new structures were introduced from 2013 in England designed to provide better care for patients. Clinical Commissioning Groups (CCGs), led by General Practitioners (GPs), started being responsible for designing and commissioning local health services in England (Department of Health, 2013). These CCGs aimed to replace the previous PCTs. The PCTs are authorized to obtain services either from a public hospital of the NHS or from a private provider (Giovanella & Stegmuller, 2014). Therefore, the opportunities for the private sector to participate in health care delivery are increasing.

3.2.1 Private vs Public healthcare provision in the UK

In the UK there is a mix of public and private health care provision. According to the OECD Health Data (2008) it is estimated that just over 12 per cent

of individuals in the UK have a duplicate/parallel health insurance. This enables people with additional private healthcare insurance to have quicker access to health services, to choose specialists and often to have higher standards of comfort when in hospital (Klein, 2005).

In recent years the NHS has made greater use of private and voluntary sector providers, in order to reduce waiting times or to provide community services such as carers for people in their own homes (Greener, 2009). For example, in 2004, the government introduced measures that helped private companies provide general medical services and included voluntary and not-for-profit sectors in the provision of public services, in order to increase their role in health care (Boyle, 2011). Plimmer (2014) has reported the amount spent on outsourcing public services in the UK has doubled to £88 billion since 2010. Similarly, following the Health and Social Care Act (2012), in community health services there has been a tripling of expenditure on independent sector activity since 2006/7 (Lafond et al, 2014 in Hudson, 2014: 282). So even though the financing remains public, there is a trend towards privatization in various aspects of the NHS (Giovanella & Stegmuller, 2014).

3.2.2 Summary

The health system in the UK is tax-financed and the primary purpose of the NHS is to offer free access to healthcare. There is a mix of public and private health care provision with approximately 12% of the population having private health insurance. The majority of NHS services in primary, secondary and community settings are now organised and financed by GP-led commissioning. In order to access NHS specialist care, patients need to be referred from a GP or they can be admitted as an emergency. In addition, they can pay themselves for a private consultation or be

referred to via a private medical insurance (PMI) scheme (Boyle, 2011). From 2013, with the implementation of the Health and Social Act (2012), new structures have been introduced to provide better care for patients, with GPs and other clinicians more responsible for commissioning health and social care with the newly established Clinical Commissioning Groups (CCGs).

3.3 The National Health System of Greece

The church in Greece played an important role in providing healthcare until the 19th century. After the Greek independence in 1830 and until the end of the 19th century, charitable organizations, military medical services and some municipal hospitals were mostly in charge of the country's health care system (Theodorou & Karakatsani, 2008). Healthcare was also provided privately by private doctors and private clinics. The role that the government played at that time was minor apart from the introduction of some vaccination programmes, regulations and sanitary instructions in order to prevent the outbreak and spread of infectious diseases. Medical officers were provided by the government to certain districts and the High Health Council (Iatrosynedrio) was established in 1834, in order to organize public health care and offer medical examinations (Economou, 2010).

Before the First World War there was no public health care provision in Greece, apart from military hospitals and charitable hospitals in the major urban areas. From the end of the 19th century a number of wealthy Greeks and charity organizations contributed to funding the building of new hospitals. Also during that period, social insurance funds for seamen, miners, civil servants and military personnel were introduced (WHO, 1996). Since the beginning of the 20th century a group of physicians protested about the absence of public health statistics and the lack

of a public health system (Theodorou & Karakatsani, 2008). In 1917 the Ministry of Hygiene and Social Welfare was established (Law 748/1917) and the few municipal and communal hospitals that existed were taken over by the municipalities and communities. The establishment of the Social Insurance Organization (IKA) in 1934, was the first significant action that the government took to increase health provision for the Greek population.

In 1953 a new legislation was introduced to establish a national health service (Law Order: 2592/1953). The objective was to decentralize health care to regional health councils and through them to district health councils. However, this law was never implemented due to the lack of structured regional policy along with the growing trend for urbanization that accompanied the reconstruction of the state (WHO, 1996). During the 1950s and 1960s the social insurance sector and social security benefits evolved and all insurance funds, other than IKA, contracted health care services from private specialist physicians in the case of primary health care services, and from public or private hospitals in the case of secondary care (WHO, 1996). This led to the expansion of the private sector as physicians started to have more private practices and the number of small-scale private hospitals grew. The healthcare situation in Greece remained the same during the dictatorship period. Following military intervention in 1967 the Generals established a dictatorship in Greece that lasted until 1974 when it was replaced by democracy. The fallouts of the dictatorship were severe and as a consequence the Greek population was divided and traumatized. However, it was during that period that plans for a comprehensive health care system were developed (Economou, 2010).

As a result of the political agenda of the socialist party that came to power in 1981, the National Health System of Greece (ESY) was finally established in 1983

with Law (L.) 1397/83. According to the ESY law it was declared that health is a "social good" and that the state should become responsible for the nation's health care. The aim was to offer citizens equal rights to high-quality health care (Ballas, 2004). Moreover, the following principles were exhibited in the reform: equity in the delivery and financing of health services; primary health care development; a type of public-private mix in healthcare provision; decentralisation in the planning process, improvements in management and community participation (WHO, 1996).

Following the establishment of the ESY in 1983, most of the private health care facilities were brought into the ESY and after 1992 new private hospitals could not be established. Also, the private hospitals that already existed were either integrated into the public sector or closed down (Economou, 2010). As suggested by Liaropoulos (1995), the initial aim of the healthcare reforms in 1983 was to increase equity in financing by expanding the role of the public sector, by limiting the role of the private sector and by reducing the relative shares of private insurance financing. However, the efforts were unsuccessful as there was an increase of the private share of care financing along with reduced equity, which had also been affected, by the growing share of private insurance funding. The increased interest in private health insurance in Greece was considered to be the result of the overall dissatisfaction with the public hospital sector and the lack of up to date diagnostic facilities in the public health services (Liaropoulos, 1995).

Initially the ESY was considered to be very popular with the Greek population and the system seemed to be working successfully, but as time passed patients' expectations increased and problems started to appear (Ballas, 2004). For example, in 1994 it was highlighted by Brian Abel Smith, the head of an investigation committee, that the amount of under-the-counter bribes to doctors, nurses and medical suppliers

was extremely high in Greece by OECD standards (Abel-Smith et al, 1994). It was also reported that the Greek National Health System was lacking planning and structure (Ballas, 2004). As stated by Close (2002), during the late 1990s the level of public dissatisfaction with the health services was the highest in the European Union.

In 2001 the Greek National Health System was subjected to a reform initiative and according to new legislation (Law 2889/2001) hospitals started operating as administrative and economic decentralized units under the control of newly established Regional Health Systems (Aletras, 2007). Afternoon outpatient clinics in public hospitals were introduced and doctors were able to offer care to private patients on a fee-for-service basis (Economou, 2010).

In terms of the service provision in Greece four services are distinguished since 1983: primary healthcare, secondary and tertiary healthcare, emergency healthcare and psychiatric healthcare (Boutsioli, 2008).

Primary Health Care in Greece is provided by: 1) the National Health System (ESY) that includes health centres, regional clinics, outpatients' departments of hospitals. As a result the healthcare financing is based on three different sources: the social insurance contribution, the state budget and private payments (Economou, 2010); 2) the public funds (e.g. IKA) that provide their services via clinics of the funds, private doctors, diagnostic centres and laboratories; 3) the Municipality; open care centres for the elderly, programmes of "help at home" along with municipal clinics, which offer primary health care, nursing and sometimes only welfare services; 4) the private sector with numerous diagnostic centres, clinics, private physicians' practices, etc.; 5) non-governmental and non-profit organizations, like the Greek Red Cross and Doctors without Borders that provide services to the general population or to immigrants and refugees in their health centres (Adamakidou, 2010).

In May 2010, Greece came under the supervision of the European Commission, the European Central Bank and the International Monetary Fund due to the country's spiralling public deficit and debts that threatened national bankruptcy. As a result, Greece signed a Memorandum of Understanding (MOU) that included health sector measures as well, that focus on reducing public expenditure. In February 2012 Greece signed a second MOU and in 2015 a third one, including similar measures. From 2011, cuts in the salaries of health care personnel have been implemented and hospital mergers and closures have been planned. As a consequence of the new measures the 'deficits of public hospitals and statutory health insurance funds are expected to increase, affecting the quality of health services and patient satisfaction with these services' (Kaitelidou and Kouli, 2012).

Since 2012 the changes in the NHS of Greece resulted in a unified central fund (National Organization for Healthcare Provision-EOPYY), which is Greece's state-owned issuer and a main provider of public health care. This organization merged most of health care funds and covers over the 98% of the insured people (Karakolias and Polyzos, 2014). Now that the financial crisis has affected the income of most Greeks, it is noted by Karakolias and Polyzos (2014), that more patients prefer to use public services. Overall, EOPYY seemed to be a promising reform but the performance of the organization up to 2013 failed to meet the expectations of the society, the state and international creditors. In addition, the health care sector seems relatively disorganized with respect to human resources (Karakolias and Polyzos, 2014).

Another impact of the crisis is the growing unemployment, which leads to an increasing number of uninsured people, who are not qualified for any health coverage following means testing. It should be noted though that the means testing has not been

updated, thus it is not based on the new social reality (Kentikelenis et al, 2014). As a result many people remain without unemployment or health benefits and many social clinics have emerged to fill in the gap.

In January 2015 the left-wing Syriza's election win can be attributed to people's frustration with the economic situation. The aims of this party are to offer a national reconstruction plan. More specifically, their objectives with respect to the health sector include access to health care for the uninsured and the restructure of the public health care system. However, at this point it is very difficult to make a new deal with the EU and reverse austerity measures.

The financial crisis also had a significant impact on mental health care provision. Anagnostopoulos (2013) suggested that there was a 55% reduction in state funding for mental health in 2012 compared to 2011, which had already decreased by 20% in 2011 compared to 2010. In addition, public and non-profit mental health providers have been negatively influenced.

3.3.1 Private vs public health provision in Greece

The health system of Greece is a mixture of public integrated, public contract and public reimbursement models, which consists of features from the public and private sectors (Economou, 2010). All services in Greece are provided both publicly and privately, except for the Emergency Care, which is only provided publicly (Boutsioli, 2008). Before 1983 the provision of health care in Greece followed the compulsory social health insurance model (Brismarck model). Currently, elements of the Bismarck and the Beveridge models co-exist (Economou, 2010).

The introduction of public-private partnerships (PPPs) in the Greek Health Sector was considered as an effective way to provide better quality health services

(Biginas, 2015). A study by Siskou et al (2008) identified the high level of use of private health care in Greece, which is linked, with the fast growth of the private sector in the last 20 years along with the underfunding of the public health care sector. Nonetheless, it is reported by Leathard (2013) that the downside with PPPs is that the emergent debts might be transferred to the next generations of taxpayers. Based on Biginas (2015) the so called "Greek Paradox" describes the situation regarding healthcare in Greece, which is considered to be the most privatized in Europe whilst the Greek population remains covered by social security. This can be justified by the lack of experienced staff in primary health services, especially in areas in the countryside or in the islands.

The significant role of private healthcare in Greece is outlined by Giokas (2001) who suggests that the Greek population have been dissatisfied with the public healthcare provision and have resorted to the private sector. It should be taken into consideration though that, as Karakolias and Polyzos (2014) reported, due to the recent financial crises more people are now turning to the public sector. There is still a large number of people though who prefer the private health care services (Adamakidou, 2010). Giokas (2001) discusses a number of aspects of the public provision that the population were dissatisfied with, for example: poor quality service provision, poor building infrastructure, services not able to meet fully the patients' needs for diagnosis and treatment with limited use of biomedical technology. Another further factor that encourages patients to turn to the private sector is the limited availability of services in the afternoon and evening hours (Adamakidou, 2010).

Similarly, Boutsioli (2008) reported that some of the factors that have contributed to the increased use of the private health sector in Greece could be: the dissatisfaction of people with the public system due to the ineffective organisation

and function of the hospitals along with bureaucracy; the insurance policies applied by both private and public insurance sectors; high quality of health services provided by private hospitals and the increase in private doctors. A study by Nikolakis et al (2002) showed that 40% of the insured in the Social Insurance Organization (IKA) resorted to a private doctor because of lack of confidence and 20% looking for a second opinion. However, Private Health Insurance in Greece does not play a major role as people usually pay by themselves. It is estimated that approximately 12% of the population is covered by private health insurance (Economou, 2010).

3.3.2 Summary

The health care system in Greece comprises of elements from both the public and private sectors. Primary Health Care in Greece is provided by: the National Health System (ESY); the public funds (e.g. IKA); the Municipality; the private sector and non-governmental and non-profit organizations. Due to the financial crisis more patients seek public healthcare and a considerable increase in the emergency units visits has been reported (Economou et al, 2014). As a consequence, the waiting times to receive public health services have increased and there is a shortage of staff. Additionally, this increase in the demand for public services led to a few NGOs providing health services and other social care services (e.g. food distribution) as well.

3.4 Mental healthcare for children in the UK

According to Gill et al (2014) child mental health care is considered an important part of the UK health system and the National Institute for Health and Care Excellence (NICE) has provided an electronic library of quality standards that consist

of many regulations that refer to children. In particular the significance of early intervention is highlighted lately, considering the "No Health Without Mental Health" initiative (Department of Health, 2011).

Children's mental health issues are progressively attracting a great deal of attention. Various documents have highlighted the importance of early intervention in the field of mental health and an effective service provision in child health care (Thompson et al, 2005). Child and Adolescent Mental Health Services (CAMHS) are specialist NHS services where assessment and treatment is offered to children and adolescents. One of the early documents that identified the tiers in which child mental health professionals work, is the Health Advisory Document (DoH, 1995). The structure of CAMHS is still based on this 4-tier system. Based on this document (DoH, 1995) the 4 tiers proposed were:

Tier 1 would offer the non-specialist primary care services via GPs, health visitors, early years' provision etc.

Tier 2 would include primary mental health workers (Gale and Vostani, 2003; cited in Thompson et al, 2005) who could take referrals and provide assessment and treatment. Based on a more recent report issued in 2014 (Child and Adolescent Mental Health, 2014) tier 2 consists of services that can be provided by professionals placed in schools or centres. A range of agencies provides these targeted services.

Tier 3 would include specialized child mental health services offered by a multidisciplinary team

Tier 4 would provide assessment and treatment in specialized day and inpatient units for more severe cases or highly specialist outpatient services.

It should be noted here that Tier 3 CAMHS provide diagnostic assessment and care for children and adolescents with autism, but sometimes specialist Tier 4 support

is required since the needs of some ASD children might be more complex. The Tier 4 Specialist ASD Services often cooperate with specialized pediatric neurodisability services aiming to provide the most appropriate care to those referred.

With respect to the referral system in the child mental health sector, it is the GP who refers children and adolescents to CAMHS services. However, in a study by Weeramanthri and Keaney (2000) it was reported that none of the GPs included in their survey were formally trained in child and adolescent mental health and consequently they would find it difficult to identify childhood disorders. Another study by Montoliu and Crawford (2002) also highlighted the importance of GPs' training in the field of child and adolescent mental health. Therefore, there is a growing need for political investment in research, professional training and national guideline development in order to promote further child and adolescent mental health (Vallance et al, 2015).

In the last years CAMHS were considered to be under pressure since it was found that two thirds of local authorities froze or cut their CAMHS budgets between 2010 and 2013 (Young Minds Survey, 2013). On the other hand, it has been reported that resources that promote child health have improved in the UK, e.g. more wards have been designed in hospitals for infants, children and adolescents (Green, 2015). Based on the most recent report of Children's and Young People's Outcomes Forum in 2014/2015 (Report of the Children, 2015) great progress has been identified in many areas concerning child health and healthcare in the UK.

Over the last years a variety of policies (e.g. DFES and DH, 2006) have promoted the child and adolescent mental health system in the UK and early intervention has been encouraged as well. In 2012 the Department of Health

published the report of Children's and Young People's Outcomes Forum where principles that aim to alter the focus of children's healthcare were identified, such as the need to promote early intervention (Report of the Children, 2012). Early intervention has been part of the reform in the UK services since the early 1990s (Van Roosmalen et al, 2012). Early intervention mental health services at Tier 2 may be provided by CAMHS, or by other agencies (e.g. voluntary sector providers). As it is stated by Weare (2000), various initiatives have also encouraged the development of interventions through schools aiming to promote mental health and to intervene early.

3.4.1 Service provision for autism in the UK

Over the past decade research has indicated that approximately one percent of the population in the UK are affected by autism (Baron-Cohen et al, 2009; Wilkinson & Twist, 2010). It has also been reported that almost three per cent of pupils in schools in England had a statement of special educational needs with eight per cent of those diagnosed with autism spectrum disorders (DCSF, 2009). A statement is a document that describes the special educational needs of children and provides information about the extra help they might need (The SEN Framework, 2014). Baron-Cohen et al (2009) identified in the UK an estimate ASD prevalence of 1.57% for children aged 5-9 years old in 2004. A more recent study by Russell and Rodgers (2014) estimated the prevalence of ASD in the UK at 1,7% which is considered relatively high. However, the increase in the diagnosis of ASD in the UK could be justified considering the broadening and changes of the diagnostic criteria, the increase of awareness, cultural factors and the decrease of stigma associated with the diagnosis (Gray, 2002; Matson & Kozlowski, 2011).

There are two main governmental policies that focus on children with autism spectrum disorder (ASD). The Autistic Spectrum Disorders Good Practice Guidance (GPG) (DfES and DoH 2002) introduced indicators for good practice in different areas of provision for children. These indicators aim to improve the development of comprehensive services or to act as a means of evaluation for established services. Secondly, the National Autism Plan for Children (NAP-C 2003) was established as a framework for the identification, assessment and provision of early interventions for preschool and primary school-aged children with ASD.

The most well known charity in the UK that leads national and international initiatives is the National Autistic Society (NAS), which was founded in 1962 by a group of parents who were later joined by people with a professional interest in autism. The specific organization works in many areas in order to help people with autism and their families live their lives with as much independence as possible (Broach, 2003).

Most methods to diagnose ASD are in accordance with broad governmental recommendations (DFES, 2002) and involve parental and professional led checklists (Baron-Cohen et al, 1992; Baron-Cohen et al, 1996; Robins et al, 2011; Ruter et al, 2003) through which parents and professionals compare observed behaviours of the child with the formal criteria for ASD (e.g. The International Classification for Diseases/ICD-10; World Health Organization, 2007). The whole process of the screening and assessment of autism is summarized in the NAP-C 2003 where a multi-agency approach is recommended; along with clear time frames for assessment; the promotion of training of professionals in the knowledge and awareness of ASD; the

active involvement of families in care planning and procedures and the creation and implementation of national networks of support for ASD.

According to ICD- 10/DSM-IV-TR (American Psychiatric Association, 2004), in order to make a diagnosis of autism a multidisciplinary assessment procedure is required. In the UK two standardized diagnostic instruments are widely used combined with clinical judgment usually of at least two or more professionals with autism expertise (Baird et al., 2006). These are: the Autism Diagnostic Interview-Revised (ADI- R) (Le Couteur, Lord, & Rutter, 2003; Lord, Rutter, & Le Couteur,1994) and Autism Diagnostic Observation Schedule (ADOS) (Lord et al.,2000; Lord, Rutter, Di Lavore, & Risi,2001).

In the UK the initial screening test for autism is usually made by the GP who will then refer the family to a health professional who specializes in diagnosing autism. Also, there are certain protocols that need to be followed with respect to the care provided for children with autism. Based on the National Collaborating Centre for Women's and Children's Health (2011) children with autism are referred to a multidisciplinary team. Most primary care trusts use a multidisciplinary team to assess children with autism that consists of a psychiatrist, a psychologist, a paediatrician, a speech and language therapist and an occupational therapist. Following diagnosis many different interventions may be suggested to the family as possible treatments for autism. Also, there are early intervention programs and a variety of support services. However, research in the UK showed that parents find the diagnostic process for ASD slow, chaotic and badly handled (Mansell & Morris, 2004).

The UK government promotes the multidisciplinary team model and encourages interprofessional working across health, education and social care. According to Parr

et al (2012) the child development centres provide most of the assessments of neurodevelopmental disorders and make the appropriate recommendations regarding intervention and care depending on the case. Child Development Centres (CDC) are part of the NHS and they offer assessment, treatment and support to children with various developmental disorders (Appleton and Minchom, 1991). The professionals who work in child development centres form the child development teams. One aspect of their role has to do with the neurodevelopmental and neurodisability assessments and another with the collaboration with education and social care services (Parr et al, 2012). One of the challenges that most of the National Health Service Trusts face has to do with the implementation of the necessary transfer to adult services. Especially, this process for young people with ASD is significantly underdeveloped (Parr et al, 2012).

In 2013 the National Institute for Health and Clinical Excellence (NICE) in cooperation with the Social Care Institute for Excellence (SCIE) published a guideline (NICE, 2013), summarising how professionals can offer treatment and support to children and young people with autism. Based on this NICE guideline all children with autism should have access to health and social care services along with mental health services regardless their intellectual abilities or any other co-occurent diagnosis. Furthermore, it is recommended in the guideline that interventions are delivered by trained professionals and mediated by parents, carers, teachers or peers. A case coordinator should also be appointed to every child/young person following an autism diagnosis, in order to act as a point of contact and the choice of intervention strategies should be adapted based on each individual's developmental needs. Additionally, it is recommended that the needs of families and/or carers should also be assessed, including their personal, emotional and social support.

Since the New Labour government of 1997-2010 in the UK, attention has been drawn to the promotion of early intervention and the importance of interprofessional working across different agencies in childhood care has been highlighted. Since then the UK government has emphasized the sustained commitment to early intervention services, in order to improve children's lives (Collins and McCRay, 2012).

3.4.2 Support for children with autism in the education system in the UK

In regards to special educational need (SEN) provision across the UK, the government has promoted the inclusion of individuals with special educational needs in mainstream schools where possible. The role of inclusion has become an essential part of the education system in the UK (Dyson & Millward, 2000). In 1994, a Code of Practice for SEN was introduced by the UK government and a special educational needs co-ordinator (SENCO) was appointed to every school. The SENCO is responsible for the identification and assessment of children with special educational needs and to provide appropriate provision for individuals within a typical classroom setting (Dyson & Millward, 2000).

Until recently teachers along with the SENCOs planned future support for children, which was known as School Action (Early years action in early years settings; DfES, 2001). In cases where the child needed extra help, external support services were provided by a specialist teacher, an educational psychologist, a speech and language therapist or another health professional (DfES, 2001). This extra support was called School Action Plus (Early years action Plus in early years settings). Different mechanisms were available to monitor service delivery, including Individual Education Plan (IEP); and Person Centred Plan (PCP). However, following the introduction of the Children and Families Act (2014) these actions are replaced by a single category named SEN support.

The Children and Families Act (2014) was introduced to improve services for vulnerable children and young people including special educational needs (SEN) and a new Code of Practice for children with SEN and disabilities was outlined. One of the key changes is the replacement of the Special Education Needs Statement (SENS, 2007) and Learning Difficulty Assessments (LDAs) by Education, Health and Care (EHC) Plans. The EHCP is a legal document that identifies the SEN needs of a child, focusing on the educational elements that were also covered by statements, but also covers the individual's health and social care needs and refers to children and young people up to the age of 25. An EHCP can be applied for by someone's school, their parents, or by the individual if they are aged between 16-25 years old.

In regards to the relationship between parents and professionals, the Warnock Report commissioned in 1974 by the then Education Secretary, Margaret Thatcher recommended the inclusion of parents in the assessment and supportive processes for children with SEN. Warnock's thinking has been reflected in the Education Acts that have followed since that time (Cole, 2005). The 2004 Children Act (DFES, 2004) underlined the importance of valuing parental contribution, including parents in the support process, along with the importance of professionals making more effort to communicate and network with each other and with parents (DFES, 2004). There are now additional services based on the Sure Start (1998) initiative (O'Connor & Futh, 2006) that provide children and their parents with support and there are also designated Parent Partnership services (DCFS, 2007) which are monitored by the Local Authorities. It has been argued that all these efforts to improve parental rights have made parents more confident to raise their concerns (Carlson & Cornwall, 2006).

A key element of the revised Code of Practice in the Children and Families Act

(2014) concerns the requirement to involve children and parents in the process. Thus, local authorities must have regard to their views and let them participate in decisions to be made. More specifically, young people (over the age of 16) and parents have a statutory right to be involved in the decision-making process with respect to assessments, service provision, planning and support. This new Code of Practice promotes more family inclusion and the personalisation of each SEN plan based on the individual's needs. Additionally, there is a focus on the positive aspects of each individual and the Government encourages cooperation between local authorities, health services, schools and families.

With respect to the Early Years Services, Eisenstadt and Melhuish (2014) noted that England adopted two successful approaches; they brought all early education and child care provision under a common regulatory framework and they merged services across agencies, mainly via the Sure Start programme. According to Eisenstadt and Melhuish (2014) the aim of the Sure Start programme was to merge health, education and social welfare services in various communities (especially in area with levels of child poverty) for all the families of children under 4 years old. In addition, the programme focuses on helping parents with their parenting skills and supporting them in order to reduce their stress. Another early year programme that was adopted in England is the Family-nurse partnership (FNP), which is based on a US nurse home visiting programme (NFP-nurse family partnership). The objective of the specific programme is to intervene early and help first-time parents and their children. More specifically, the services are provided by a nurse home visitor who focuses on the social and emotional health of the family as well. However, in England the specific services are provided only to mothers under 20 years old and a variation is provided to a wider group. Political will and the involvement of Her Majesty's Treasury in

policy formulation are considered the most important facilitators of these changes in the early years services. The Treasury also promotes the cooperation of the departments of health, education and employment on social policy issues (Eisenstadt and Melhuish, 2013).

3.4.3 Stigma and parents' experiences in the UK

There are various programmes and campaigns in the UK that are conducted in order to combat social stigmatization towards disability and mental illness (Stigma-a review of the evidence, 2010). However it should be taken into account that most of them are focused on adults. Standard One of the National Service Framework for Mental Health (Department of Health, 1999) has contributed a great deal to the fight against discrimination to mental illness. Actions to address these issues are often carried out through several professional organizations along with health and social services departments (Papadopoulos, 2009).

There is evidence from the UK's Department of Health (2007) that non-stigmatizing attitudes in relation to disability and mental illness are increasing in the British culture, but that stigma in general is still present, particularly in more rural and poorer socioeconomic backgrounds. Nonetheless, it is reported by Papadopoulos (2009) that despite the fear of being stigmatized when accessing mental health services, people in the English culture do not hesitate to look for the necessary care and treatment. A study by Rose (2007) drew attention to the inadequacy of knowledge in young people with respect to mental health issues that might instigate more discriminating behaviours towards other young people with mental health problems. For this reason a growing number of national campaigns are carried out aiming to change the situation. For example, after the Changing Minds campaign, led by the

Royal College of Psychiatrists, several improvements in this area were reported (RCPsych, 2003).

In a child's early years, after the onset of autism, parents experience a very difficult and stressful period as they are struggling to understand their children's problems and as they are looking for an accurate diagnosis and treatment for their child. This period comes to an end when the diagnosis is received and the child is placed in appropriate treatment (Marcus et al, 1997). According to a study conducted in the UK by Calzada et al (2012), parents of children with autism reported that they tried to avoid discussing the diagnosis with their child as they did not want them to feel abnormal and stigmatized. Also, some of the parents expressed concern about other people treating their child differently because of the diagnosis (Calzada et al, 2012). In addition, Hodge (2006) suggested that some professionals do not include parents in the final decision making process that determines whether their child has ASD, which leaves parents confused. Moreover, it is reported that parents in the UK were often unhappy with the imbalanced focus on a child's difficulties as opposed to strengths (Hodge, 2006).

Howlin and Moore (1997) conducted a large survey of parental experiences of the diagnostic process with children diagnosed with ASD in the UK. The results showed that the level of parental satisfaction was related to the age of the child when the diagnosis was made. Parents whose children were diagnosed earlier appeared to be more satisfied than the ones whose children were diagnosed over 5 years old. A link was also found between the degree of satisfaction both with the process of diagnosis and with the help received, in addition to the length of time parents had to wait before the final diagnosis.

Attention is also paid to the process of communicating a diagnosis of autism to

the parents in the UK. Based on the National Institute for Health and Clinical Excellence (NICE, 2011) the guidelines propose that professionals should give sufficient time to parents; they should also let the parents/carers lead them and give them time to act upon the news of the diagnosis (Abbott et al, 2012). Furthermore, the professionals involved are advised to be sensitive, explanatory and to provide a written report along with a follow-up assessment. Abbott et al (2012) utilized qualitative methodology in order to investigate the experiences of nine parents in North East England. The researchers focused on how the parents perceived the feedback session when they received the initial diagnosis of autism for their child. Parents felt significant amount of stress following the diagnosis and confusion as well. The authors noted that even parents who expected the diagnosis felt a great deal more intense feelings than originally expected.

The diagnostic process, forward planning and reviews aim to help parents and professionals care for children with autism. In a study by Keenan et al (2010) in the UK, parents representing 100 children with ASD and 67 multidisciplinary professionals reported their experiences of these processes and the findings showed that diagnosis and "statementing" took extended periods of time and did not result in satisfactory future planning for the children and their families. Parents and professionals agreed that improvements were necessary regarding timing and review procedures of diagnosis, statementing and forward planning. The results were similar to those of previous studies (Cassidy and Morgan, 2006; Jones et al, 2007) that showed diagnosis as a difficult process that can take a long time. In addition, the Keenan et al (2010) study showed that the whole process was distressing, unclear, difficult to understand for parents and families and did not lead to clear advice on how to proceed after diagnosis (Keenan et al, 2010).

When caring for a child with ASD it is important for parents to have a good relationship (Brown, 2011). However, in many situations parenting a child with autism affects the parents' relationship (Broach et al, 2004). In a study conducted in the UK by Bromley et al (2004) interviews were undertaken with 68 mothers of children with autism and over half of them screened positive for significant psychological distress. Also, it was found that the distress was associated with low levels of family support and mothers were more likely to report low levels of support if they were a lone parent.

3.4.4 Summary

In the UK the initial screening test for autism is often made by the GP who will then refer the family to a health professional who specializes in diagnosing autism. Some primary care trusts use a multidisciplinary team to assess children with autism, and following diagnosis, many different interventions are usually suggested to the family as possible treatments for autism.

In regards to special educational need (SEN) provision across the UK the government has promoted the inclusion of individuals with special educational needs in mainstream schools where possible. The special educational needs co-ordinator (SENCO) is responsible for the identification and assessment of children with special educational needs and to provide appropriate provision for individuals within a typical classroom setting (Dyson & Millward, 2000).

Regarding parents' experiences research suggests that some professionals do not include parents in the final decision making process that determines whether their child has ASD, which leaves parents confused. Also, some parents of children with autism in the UK reported that they tried to avoid discussing the diagnosis with their

child, as they do not want them to feel abnormal and stigmatized. With respect to stigma towards disability and mental illness, non-stigmatizing attitudes are increasing in the British culture, but research shows that the stigma in general is still present.

3.5 Mental healthcare for children in Greece

One of the most significant milestones in the child mental health sector in Greece was the establishment of the first child psychiatry department in a general paediatric Greek hospital in 1979 by Professor John Tsiantis (Kolaitis et al, 2012). In regards to the reforms in the child and adolescent mental health sector another significant change in Greece was the closure of the Child Psychiatric Hospital of Attiki, which was established in the 1960s. Consequently, all the children who were hospitalized there (mostly with severe intellectual disability) were transferred to more modernized community facilities.

In the early 1980s many child mental health services were founded. Since then there has been a modernization of the child psychiatric system under the EU Regulation 815/1984. Since the mid 1980s there has been an effort to review and redesign the mental health system in Greece (Christodoulou et al, 2012). The European Union has been assisting financially and technically with the implementation of this reorganization and the reform is based on the EU Regulation 815/1984 (1984-1994) and on the Psychargos programme (the latest revision of the programme by the ministry of Health and Solidarity covers the period 2011-2020). The Child and Adolescent Mental Health Services in Greece are regulated under the National Health and Welfare Policy (Pejovic-Milovancevic et al, 2014).

At the end of 2010 the European Union requested an evaluation of the psychiatric reforms and an independent team from abroad along with an expert Greek

team comprised the evaluation team. Based on the findings most of the initial aims of the programme were successfully reached. However, it was mentioned by Loukidou et al (2013) that irregularities between urban and rural areas were noticed and some of their goals showed variation. Based on Christodoulou et al (2012) the effort to transform the mental health system has not been totally successful. According to the evaluation of the National Action Plan Psychargos in the period 2000-2009 only 30% of the planned psychiatric services for children were actually established (Anagnostopoulos, 2013). Kolaitis et al (2012) reported that in 25 of the 52 prefectures of the country there are no child psychiatric services. In general, there is intent to establish more child psychiatric services in the Attica Prefecture (where the city of Athens belongs to) and due to the crisis the plan to reform the child psychiatric services has been cancelled. It should be taken into account though that thanks to the Psychargos Programme a range of community mental health services were created and the deinstitutionalization of chronic psychiatric hospital patients has occurred (Loukidou et al, 2013).

Moreover, as a result of the evaluation that was requested at the end of 2010 the Greek Ministry of Health changed the Psychargos Plan in 2012 based on the findings, but the current financial situation of Greece might have a negative effect on the implementation of the necessary changes (Loukidou, 2013). It is hopeful though that in July 2013 the Greek government agreed with WHO in order to receive their support with respect to the planning of health care reforms and in September 2013 a new health voucher programme was financed by the EU in order to cover 230000 beneficiaries for 2013-2014 (Kentikelenis et al, 2014).

Despite all the positive developments the CAMHS in Greece is still considered to be inadequate in fulfilling the needs of children, adolescents and their

families (Kolaitis et al, 2012). Especially during the last years, due to the financial crisis, a growing demand for public child and adolescent psychiatric services has been noted (Christodoulou et al, 2012). This increase can be justified by the fact that there is an increase in the psychopathology of children and adolescents due to the impact the crisis had on most family dynamics and because more and more people turn to the public sector and terminate the private services their children used to attend.

There are still issues in the mental health field that need to be addressed, such as sectorization, development of primary care policies, inter-sectorial coordination, development of forensic services along with long-range planning (Christodoulou et al, 2012). Additionally, there is a growing need to focus more on the provision of care to the most vulnerable groups, like children and adolescents, where there are still many deficiencies. For example, there are still many problems with the provision of care to people with autism. However, the current situation is difficult to change due to the economic recession as the child and adolescent mental health services have been severely affected and the best solution is for the existing services to maintain a satisfactory level of function. The negative effects can be recognised both in the child psychiatric services and in the extended environment in which the children are growing up. As it is recommended by the World Health Organization it is important to make good use of the present resources and link funding to accreditation systems and assessment of provider performance (WHO, 2011 in Christodoulou et al, 2012). Anagnostopoulos & Soumaki (2013) conducted a survey in a sample of public and private child psychiatric institutions in Athens, Piraeus and Thessaloniki comparing data from 2007-2011. Based on the results there was a 39,8% increase in new cases in public outpatient services for children and 25,5% for adolescents and there was a drop

by 35,4% in the private care. By 2013 the waiting time in most Child and Adolescent Mental Health Services had tripled (Anagnostopoulos & Soumaki, 2013).

Children with autism in Greece are usually referred by paediatricians to child psychiatric services (Volkmar et al, 2007). Care for people with autism has been provided by mental health and welfare services. However, mental health services are limited to the large cities (Volkmar et al, 2007).

3.5.1 Service provision for autism in Greece

The interest in autistic disorders started growing in Greece in the early 1960s (Anastasopoulos et al, 1964) and the use of the DSM-IV (American Psychiatric Association, 1994) and the ICD-10 (WHO, 1992) has contributed to the increase in knowledge regarding diagnosis and care provision for children with autism. This knowledge has been strengthened by the evolution of child psychiatry as a separate discipline from general psychiatry in Greece in the early 1980s (later than in the UK where child psychiatry became a separate specialty in the 1940s). In addition the growing dissemination of information on autism was influenced by the European Community Charter of Recognition of the Fundamental Social Rights of the Disabled, the related legislation of the European Community for people with special needs and the foundation of the parents' Greek Autism Society for the protection of autistic people (Gena, 2002). Moreover, under the Law 1143/81 in 1981 special centres for the care of children and parents were established, in order to provide diagnostic and counselling services across different areas of Greece. With respect to the rural areas some of the establishments offer their services via mobile units. In addition some Medical Pedagogical Centres have been developed in the major cities of Greece offering primarily diagnostic services. In 1992 the Greek Society for the Protection of

Autistic People was established and they have contributed to most of the advances in the field of autism in Greece. Later on, with Law 2817/2000, 54 Diagnosis Evaluation and Support Centres were established (KDAY). Nonetheless, the KDAYs have significant challenges especially having to do with infrastructure. Assessments of children with autism are also conducted in child psychiatry clinics of children's hospitals. Prior to the Greek Law 2817/2000, children with autism were mostly offered care and support in asylums, at home or other residential entities and they were not included in mainstream education (Syriopoulou-Delli et al, 2011).

In Greece, unlike the UK, General Practice is very under-developed, so a child can only be referred to a specialist team by a paediatrician or the parents can refer themselves. The Diagnostic Assessment and Support Centres that were established in the capital cities of each prefecture in Greece under the Law 2817/2000 offer diagnosis, assessment and care mostly to children between the ages of 3 and 22 years. A multidisciplinary team that evaluates children with autism is placed in each centre and consists of a psychiatrist, a clinical psychologist, a speech and language therapist and a social worker. These professionals use various psychoeducational tools to measure: the skills/abilities of children with autism, the autistic symptoms, the neurological state and function of the central nervous system, the IQ, the learning and language skills, the relationship of the child with their family, their emotional wellbeing and their social skills (Gonela, 2006). The assessment procedure is based on an interview with the parents and the child. Cognitive abilities as well as communication and social skills are assessed. The diagnostic accuracy is reinforced by the use of specialized instruments such as the ADI-R (Lord et al, 1994) and the Diagnostic Interview for Social and Communication Disorders (Wing, 1999), the Autism Diagnostic Observation Schedule-Generic (Lord et al, 1998), the

Psychoeduactionsl Profile-Revised (Schopler et al, 1990) and the Adolescent and Adult Psychoeducational Profile (Mesibov et al, 1988).

Most children with autism are referred by their parents and often with serious delays, as they do not know the existence of relevant services (Papageorgiou, 2005). This may be caused by the lack of public awareness. Another reason for parents delaying the diagnosis might be that they want to avoid social stigmatization, since the social pressure with respect to issues of disability is more intense in Greek communities (Argyrakouli & Zafiropoulou, 2003). Following the referral children are assessed by a number of professionals of different disciplines and often receive different diagnoses.

A study carried out by Efthimiou et al (2013) in Greece suggested that 25 out of 7,661 had an Autistic Disorder, based on DSM-IV. The initial assessment is usually given by the paediatrician, who in turn, refers children to a child development clinic for an official assessment and possible diagnosis (Papageorgiou, 2005). However, these clinics, as it was mentioned earlier are usually established in large cities. In addition, early intervention programs are limited in Greece and due to the disorganization of the health system there is not enough cooperation among separate entities that provide support and care to children with autism and their families. As it is also suggested by Papageorgiou (2005) autism is diagnosed at first assessment in one third of the cases, which could be due to inadequate training of professionals in this field.

Moreover the financial crisis in Greece has affected the units that deal with developmental disorders and the impact has been significant. For example, Perivolaki (1983), a well-known establishment for children with autism, where diagnosis, day-care and overall support is provided, has shut down two of its three community units

(Anagnostopoulos, 2013). Furthermore, there is a growing need in Greece for different departments (e.g. health and school) to work together in order to provide better support to the community of families of children with autism (Anagnostopoulos, 2013). Giannakopoulos et al (2014) reported in their findings that very few educators work in partnership with families and local mental health services.

Based on a study by Stampoltzis et al (2012) the average age of diagnosis in Greece was six years of age and about 78% of the children who participated in their study had private speech, occupational or music therapy at least once per week. Stampoltzis et al (2012) also reported that most children with an ASD are not offered the appropriate early intervention services and they often receive suitable support when they start primary school. This situation could be justified by the lack of clarity in the policies and procedures that refer to early childhood education centres and children with mental health problems or developmental disabilities (Giannakopoulos et al, 2014). However, Stampoltzis et al (2012) support the notion that children with ASD share common characteristics among developed countries. Overall, the variety of early childcare in Greece is relatively limited considering other European countries (Petrogiannis, 2010).

Despite all the difficulties reported above in the last 20 years there is an overall improvement in the service provision for autism in Greece and in the area of child and adolescent mental health in general. For example, many non-governmental organizations are providing mental health services at the moment in several areas of the country, they have developed centres for specific groups such as children with autism and they have secured funding for research projects on various aspects of mental health (Kolaitis et al, 2012).

3.5.2 Support for children with autism in the education system in Greece

In 1985 the policy for the education for children with disabilities changed significantly and Law 1566 had a separate section for special education. In 2000 the Greek state made a move to create a legislative framework, with the institution of Law 2817/2000 from the Ministry for National Education and Religious Affairs, where it is indicated that people with special needs are those with sensory-motor difficulties, mental deficiency, special learning difficulties, and complex cognitive, emotional and social difficulties as well as autistic persons and people with developmental disorders (Syriopoulou-Delli, 2010). With Law 2817/2000 several education issues for children with special educational needs were managed. In addition the same Law promoted the establishment and function of special education schools and the formation of a Special Education Department in the Pedagogical Institute (Anagnostopoulos, 2013).

In regards to Special Educational Need (SEN) provision in Greece a new legislation was voted in 2000 (2817/2000 - Government of Greece 2000) that the "special classes" that existed in schools for children with special educational needs would be renamed to "inclusion classes", reflecting thus the increased emphasis that was placed on the practice of inclusion. This law introduced the design and development of individualized educational plans for students with SEN, who had to be incorporated into the mainstream curriculum with the support of trained teaching staff and it was emphasized that students with SEN should be trained in the general classes along with the other students (Kalyva, 2008).

An amendment of the initial Law came in 2008 to make the inclusion of special educational needs children compulsory in public mainstream education (Law 3699/2008). However, many teachers that support children with autism are not

qualified nor trained sufficiently (Syriopoulou-Delli et al, 2012). Most early childhood educators are unable to respond adequately to children's and families' mental health problems and developmental disorders (Giannakopoulos et a, 2014).

Special needs education in public schools can be offered in inclusive classes within the mainstream school, in mainstream classes with one-to-one support, in special schools, in special classes within hospitals/ institutions or at home. In order for a child to be part of a special needs education programme they must be assessed at an evaluation centre (Differential Diagnosis, Diagnosis and Support for Special Educational Needs-KEDDY) or at an approved paediatric or psychiatric facility, to obtain certification of their problems (Kalyva, 2008). Special Educational Needs Co-ordinators (SENCOs) have not been officially introduced, yet, in the Greek educational system. However, there are support teachers either working in resource rooms or instructing students with SEN in general classrooms through the so called "parallel support programs" (Agaliotis & Kalyva, 2011). With regards to the special education in the early years Petrogiannis and Dragonas (2014) suggested that the future of integrated nurseries for toddlers with special needs is doubtful due to the economic recession and they are provided by only a small number of municipalities. In addition, special agencies like the Greek Society for the Protection of Autistic People support them in order to improve the development of these children and offer them the same education and communication experiences as their typically developing peers (Petrogiannis and Dragonas, 2014).

3.5.3 Stigma and parents' experiences in Greece

Greece was historically an agricultural country and it has only been since the past 50 years that Greece has transformed into a late-modern society (Petrogiannis

and Dragonas, 2014). As a result, the initial norms and values that used to form the traditional patriarchal family might still influence up to a certain level the Greek society. As described by Tsibidaki and Tsamparli (2009) the family unit and religion still play a major role in the Greek culture. In Greece 98% of the population follow the Greek Orthodox religion (Papadopoulos, 2009) and religion is present in different aspects of the society, e.g. in education children are taught obligatory religious courses (Tsibidaki and Tsamparli, 2007).

Families with children with a disability consider their faith in God and the relationship with a priest or even the whole congregation an essential source of support, both emotional and financial (Tsibidaki and Tsamparli, 2007). Based on Hofstede's theory (1997) on culture the Greeks as a nation are not comfortable with vague situations and the Greek Orthodox religion might have instigated the high levels of "uncertainty avoidance", thus the low levels of tolerance for uncertainty, that define the country. The culture in which children grow up forms their lives, characters and attitudes towards difference, disability and mental health issues as they internalize the different social and cultural rules (Vlachou, 1997). For example, in Greece people with a disability are not expected to adopt social roles and be active members of the society (Westbrook et al, 1993). Research conducted in the UK on UK-migrant Greeks suggested that they tend to hide any mental health issues in the family and they might even turn down a mentally ill family member and use psychiatric services only in extreme situations, which supports Hoffstede's theory on "uncertainty avoidance" since mental health problems create ambiguity for the future (Papadopoulos, 1999).

Mouzas et al (2008) reported that there is a negative attitude towards mental illness in general in Greece. In addition, research suggests that stigmatizing attitudes

towards disability and mental illness exist in the Greek culture (Arvanity, 2008; Tzouvara and Papadopoulos, 2014 and Mouzas et al, 2008). Mouzas et al (2008) also identified an association between religiosity and mental illness stigma. Therefore, it seems crucial to increase anti-stigma campaigns along with general knowledge about mental illness and involve trusted members of each community in order to promote anti-stigma attitudes in the more traditional parts of every community.

In a study by Papageorgiou and Kalyva (2010) most of the parents of children with an ASD (48.2%) reported positive attitudes coming from family, social (39.8%) and work environments (39.1%); 1/3 of the parents that participated in the study mentioned that they felt rejected from others around them and 1/3 had not revealed to colleagues that they have a child with ASD due to fear of stigmatization. Particularly men tended to hide this information and as Papageorgiou and Kalyva (2010) described, this could be due to the fact that men don't want to be pitied or they could be more worried about being stigmatized. According to Gena (2006), Greek parents of children with autism have reported that the progress and future of their children along with their adjustment have been the most common causes of anxiety for them. The difficulty of Greek society to accept a child with autism is usually caused by the lack of suitable therapeutic programmes, which is one of the main stress factors for the parents, along with the fear of uncertainty that was mentioned earlier. The level of support that parents receive from their immediate family environment, in addition to the acceptance of the "problem" from the grandparents and other relatives, are also decisive factors for the well-being of the family in Greece. A timely and valid diagnosis accompanied by a thorough and comprehensive explanation to the parents regarding the disorder is crucial for their better adjustment (Gena, 2006).

As it is argued by Dycehs et al (2007), the impact of any impairment can be

better understood in the context of the person's experience of cultural and social networks. Thus, the cultural background might affect which behaviours of a child with autism are conceived as problematic. Papageorgiou and Kalyva (2010) reported that parents in Greece perceived deficits in communication, social and self-help skills along with the educational and behavioural difficulties as the most challenging aspects of autism. Also, it was noted by the authors that the parents mentioned feelings of embarrassment when they were in public and that their support systems were inadequate. The stress levels of the parents were also found high in the Papageorgiou and Kalyva (2010) study which confirms findings of similar studies that were carried out in Greece (e.g. Konstantareas and Papageorgiou, 2006).

According to a study by Argyrakouli & Zafiropoulou, (2003) with Greek mothers of children with a disability, it was found that many Greek mothers feel a prolonged sense of loss, despair and hopelessness if they have a child with a disability, like autism. The Greek culture seems to place higher importance on social status compared to the English culture. In addition, the Greek culture places strong emphasis on social criticism and as result Greek mothers of children with autism may feel isolated (Argyrakouli & Zafiropoulou, 2003). However, some aspects of the Greek culture lead to positive self-esteem for mothers. According to the results of the study by Argyrakouli & Zafiropoulou (2003), Greek mothers of children with a disability who have higher education and more qualifications tend to be more confident. This could be due to a more realistic view of their child's situation and the ability to try to find appropriate care. Moreover, in the same study positive self-esteem was associated with larger family size, suggesting the idea that "the typical child will make-up for the disabled one" (Pitten, 2008:4).

Parents, specialists in the field and caring citizens have been struggling to

accomplish the creation of diagnostic centres, special education schools, day centres, boarding schools and other services that provide children with autism and their families a better life. The persistence of these groups of people is leading to the progress of research and the role of the parents of children with autism is the most important. Since 1992 parents established the " Greek Society for the Protection of Autistic People", an organization that involves parents of children with autism and professionals working in the field. This society is very active and cooperates with Autism-Europe as well. Also, there are many regional Associations of parents of children with autism all over Greece (Gonela, 2006).

3.5.4 Summary

In Greece parents can be referred to a specialist team by a paediatrician or they can refer themselves. Most children with autism in Greece are referred by their parents and often with serious delays, as research suggests they do not know about relevant services. Another reason for parents delaying the diagnosis might be that they want to avoid social stigmatization. Research suggests that stigmatizing attitudes exist in the Greek culture (Arvanity, 2008; Tzouvara and Papadopoulos, 2014 and Mouzas et al, 2008). The financial crisis in Greece has also affected the units that deal with developmental disorders due to the reduced staff and closure of several units and the impact has been significant. For example, Perivolaki (1983), a unit where diagnosis, assessment and overall support are provided has closed two of its three community units (Anagnostopoulos, 2013).

In regards to special educational need (SEN) provision in Greece, since 2000 an increased emphasis upon the practice of inclusion has been noted. Individualized educational plans were introduced for students with SEN, who had to be incorporated

into the mainstream curriculum with the support of trained teaching staff and it was emphasized that students with SEN should be trained in the general classes along with the other students (Kalyva, 2008). However, Special Educational Needs Co-ordinators (SENCOs) have not been officially introduced, yet, in the Greek educational system.

3.6 Main similarities and differences between Greece and the UK in regards to autism

The British NHS is considered a comprehensive public, low cost system and a pioneer of public private partnerships. For these reasons Greece has followed some patterns of healthcare provision already developed in the UK (Boyle, 2011). However, an important difference between the two healthcare systems is that in Greece there is an absence of family physicians (GPs) in order to act as a point of reference to health services and to refer patients into the NHS (Karakolias & Polyzos, 2014). So in the UK it is the GP that makes the initial screening of a child with possible autism and will then refer the family on to specialist services within the NHS.

In Greece the GP screening and referral system for childhood autism does not exist. This could be argued as the reason why many children are referred with serious delays, in addition to a lack of public awareness. In Greece children and parents can only be referred by a paediatrician or they can refer themselves to a specialist team, and it has been reported that often parents have difficulty in finding how to access these teams. Furthermore, in Greece parents often choose to consult with a private paediatrician because of the long waiting lists in the public sector. Therefore, one of the main differences between Greece and the UK in regards to the service provision for autism is the initial referral process.

Also, it should be noted that in both the UK and Greece the service provision for autism is part of the Child and Adolescent Mental Health Services, but the CAMHS in Greece are not organized around a four-tier system as in the UK. Although the referral system and CAMHS organization are different between the two countries the members of the team that children with autism are referred to are very similar, as are the diagnostic tools that are used to assess autism. In both countries the official diagnosis of autism is offered by public healthcare specialists. However, in Greece there are only a few NHS centres nationally that can provide this service, which makes the waiting for a diagnosis even longer. Also, due to the lack of organization in some of the public settings that offer diagnosis and treatment, sometimes parents prefer to go to private diagnostic centres and pay for the diagnostic assessment and treatment of their child. Moreover, compared to the UK, in Greece there is a lack of appropriate prevention and health promotion services and insufficient staff and equipment in the rural primary care centres (Simou et al, 2015).

Nonetheless, in the UK there is also a need for political investment in research, professional training and further promotion of child and adolescent mental health (Vallance et al, 2015). The two countries may vary in their referral system and aspects of their health care provision but when it comes to autism and child mental health provision they face similar challenges, such as financial constraints and lack of practitioner training (Vallance et al, 2015).

Another area that the two countries differ is the special educational need (SEN) provision within the education system, even though both countries have policies that emphasize the role of inclusion of individuals with special educational needs in mainstream schools. Since 1994 a special educational needs co-ordinator (SENCO) has been appointed to every school in the UK. However, in Greek schools SENCOs

have still not been officially introduced. As a result, it is more difficult for children with autism to progress in the typical classroom setting. Sometimes, Greek educators express concern about the utility of inclusion. Their main arguments are: 'time shortage, lack of specialized knowledge on their side, the high demands of the curriculum, and potential problems in the academic progress of non-disabled students' (Agaliotis & Kalyva, 2011: p. 545). Additionally the early intervention sector in Greece is relatively underdeveloped compared to the early childhood services provided in the UK. Relevant training can help early educators to identify children experiencing problems and intervene early in order to give them a better opportunity to thrive (Giannakopoulos et al, 2014).

A similarity between the two countries is the role of voluntary organisations that support parents and promote services for autism in both UK and Greece respectively. The National Autistic Society (NAS) in the UK was founded in 1962, and the " Greek Society for the Protection of Autistic People" in Greece was established in 1992.

To conclude, the differences between the two countries should also be considered when discussing the perceptions of autism in the two countries. Wilder et al (2004) reported that many behaviours, like aggression, lack of attachment, poor social and communication skills along with lack of emotional expression might originate from differences in culture. Perepa (2014) suggests that the way parents perceive their children's difficulties might influence the outcome of an intervention. For example, some parents might perceive specific behaviours of their children as problematic whereas others will not. Therefore, it is important for them to be included in the process of developing an intervention, in the planning, and it is equally important to identify the value a specific behaviour might represent for the parent. Perepa (2014) also identified the impact of the parents' cultural background on the

perception of autism in general.

As previously discussed the Greek culture seems to place higher importance on social status and places strong emphasis on social criticism, which can lead parents to delay the diagnosis in order to avoid social stigmatization (Argyrakouli & Zafiropoulou, 2003). Nevertheless, the issue of stigmatization is evident in both countries. However, in the UK anti-stigma campaigns have contributed to an increase in positive attitudes towards mental illness and developmental disorders (Evans-Lacko et al, 2013). The decrease of stigmatizing attitudes attached to mental health issues and disability in the UK could be explained by improved education through the media and via the broadening of awareness in society thanks to the increased presence of community psychiatric services (Papadopoulos, 2009).

Chapter 4 Speech and Language Interventions

4.1 Introduction

This chapter is one of three chapters that present and discuss findings of studies investigating the types of treatment that are the focus of this study: Speech and Language Therapy, Psychotherapy and Occupational Therapy. The aim of this chapter is to provide an overview of different techniques used in speech and language therapy.

Research studies demonstrate that children with autism can have significant speech and language deficiencies (Volkmar et al, 2009) and children with autism are considered to be limited in their communicative abilities (Tager-Flusberg, 1999). Lack of verbal and non-verbal initiations appears often in children with autism and they usually show deficiencies across a variety of linguistic domains. As a result, intervention research focused on the improvement of those skills is important regardless of whether a child with autism uses verbal means of communication or uses augmentative and/or alternative systems of communication (Koegel, 2000).

Over the years augmentative and alternative communicative systems have been explored and are now available for children with autism in order to help them expand their communication repertoires (Magiati & Howlin, 2003). Even so, the interrelationship between language and other deficits in autism has made the need for research in this area even more important (Koegel, 2000). These impairments are connected with deficits in understanding how other people think and with other aspects of the disorder, especially with social functioning (Kjelgaard & Tager-Flusberg, 2001).

As seen in chapter two, a number of factors have been found to link to language development and these are often used as the basis for speech and language therapy in this area. For example, Kasari et al (2008) suggested that joint attention and object play are significant predictors of expressive language development and Toth (2006) has reported a connection between joint attention skills and language ability as well.

Epidemiological studies by Derby et al (1992) and Iwata et al (1994) suggest that as many as 75–80% of behaviour problems in autism may have a communicative function (as cited in Koegel, 2000,p.5) and according to Volkmar et al (2004) approximately 25% of children with autism do not develop functional speech. Communication skills are considered to be necessary to form social and personal relationships and they affect behaviour, self-regulation, and learning. In a study by Roulstone et al (2012) it was reported that parents considered that improvements in their children's communication skills could lead to increased social inclusion and independence. Individuals with and without autism need to be able to interact socially and in order to achieve this ability, according to Bloom and Lahey, 1978 (cited in Koegel, 2000,p.7) children "must learn the rules of language use for deciding which forms to use in different contexts, for learning when and how to say what to whom".

It is widely acknowledged that difficulties in communication is a core feature of ASD and there is a growing body of research that focuses on providing effective methods in order to improve the communication skills of children with autism (Goldstein, 2002). A number of studies have attempted to examine the effect of language interventions on autism and to use language interventions in order to change communication skills in children with autism. These studies cover a wide range of participants and methods, from those involving individuals who are low functioning

and require picture based programmes such as the Picture Exchange Communication System (see section 4.2.1) to those which address higher communication skills such as pragmatic difficulties. These studies are now discussed.

4.2 Language interventions in children with autism

The present review aims to investigate the effect of speech and language therapy with children with autism by reporting information on several programmes that are used to improve language and communication skills in this group of children. This review discusses various types of speech and language therapy interventions (as seen in tables 12 and 13) in order to allow a better understanding of its use with autistic children. Also, in this section a description of literature search strategy is encompassed along with the criteria used to include and appraise the studies.

The literature review conducted entailed a computerized search for relevant papers from various databases. The SCOPUS, PsycINFO, CINAHL, Medline, ERIC and Cochrane databases were searched in 2013 and again in 2015 using the following keywords: autism, ASD, speech, language, therapy, pathology, intervention, treatment. The above search terms were combined with the universal 'Boolean operators'. Also, word endings were 'truncated' with the commonly used asterix standing for any or no characters at the end of a word.

In the first stage of selection process, all papers whose title or abstract were clearly not relevant to this review were excluded, and a total of 1280 papers remained. In the second stage abstracts of identified papers were screened for the following inclusion criteria: a SLT intervention was provided, the target population was children with ASD, the papers were available in English and the studies were published between years 2000-2015. The specific dates were chosen in order to offer the most

up to date evidence. Thus, studies were excluded if their focus was not on the use of speech and language therapy and if they included groups of adolescents and adults or children with developmental disorders not on the autism spectrum. On inspection, fifty studies were identified as meeting the inclusion criteria and were categorised as follows: 19 addressed the Picture Exchange Communication System (PECS), 10 the Functional Communication Training (FCT) and Speech Generating Devices (SGD), 8 the Natural Language Paradigm (NLP) and other parent implemented interventions, 4 the Naturalistic intervention techniques and 4 studies discussed the Denver Model, PROMPT and ALM methods. An overview of these papers is provided in sections 4.2.1-4.2.12. Several techniques have been reported in these studies to be beneficial for children with autism in regards to the improvement of their language and communication skills. The methodology and results of these studies are varied and these will be discussed in this chapter.

Moher (2009) presented a helpful guideline to use when conducting a systematic review, in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement that also guided this literature review. When conducting a review there are different levels of evidence-based practice available. Five levels of evidence (Sackett et al, 1996) have been described: Level I contains systematic reviews, meta-analyses, randomized controlled trials; Level II includes two groups, nonrandomized studies (e.g., cohort, case-control); Level III incorporates one group, nonrandomized (e.g., before and after, pretest and posttest); Level IV embodies descriptive studies (single-subject design, case series) and Level V contains case reports and expert opinion that include narrative literature reviews and consensus statements. Level I and II are considered to be the most effective and conclusive for evidence-based practice (Portney and Watkins, 2007). In tables 12 and 13 the order of

the studies reflect the strength of the findings in relation to the types of study design.

It should be taken into consideration that speech and language therapy practice is often not pinned to any of these particular techniques included in this review and tends to be more eclectic and individualized. Several speech and language therapy approaches have been developed aiming to promote the communication skills of children with autism. However, the fact that children with autism present with significant heterogeneity makes it more difficult to conclude that there is one technique that fits all children with autism (Howlin, 1998). Many researchers support the notion that speech and language intervention for children with autism should be individualized. Practitioners use a number of programmes that they tend to adapt based on knowledge from external systematic research along with their personal clinical expertise, in order to fit individual children and families (Law, Roulstone & Lindsay, 2015). Thus, the role of speech and language therapists is multifaceted, as they should consider the developmental profile of each child and proceed accordingly (Prelock, 2002).

There is limited evidence regarding the effect of general eclectic speech and language therapy practice on the language, pragmatic or functional communication of children with autism. In a study by Fernandes et al (2011) fifty children and adolescents with autism (mean age:9,3 years) received 6 months of speech and language therapy and were assessed after 6 and 12 months of the therapy onset. The functional communicative profile of 96% of the participants improved after treatment, even if it lasted only 6 months. The results suggest that speech and language therapy can be beneficial for children with autism even when it is initiated at an older age, e.g. in adolescence. More robust evidence on the outcomes of speech and language

therapy practice was provided by Adams et al (2012). The researchers conducted a single blind randomized controlled trial (RCT) to investigate the outcomes of an intensive social communication intervention offered to children with pragmatic language impairment with or without autistic features. A total of 88 children (aged 5-10 years) were involved and they were randomly assigned to the Social Communication Intervention Programme or to the group that received treatment as usual. It was also reported that the majority of the participants had Pervasive Developmental Disorder or Autism Spectrum Disorder but they indicated that they excluded children with severe autism at the start of the study. Significant intervention effects were found for the social communication intervention (22% improved in conversational quality and 28% in social communication) compared with treatment as usual (5% improved in conversational quality and 4% in social communication). Therefore, the results of the study demonstrated an improvement of the conversational competence and functional social communication for the children who received the intensive social communication intervention. Additionally, it was implied that the specific intervention may be beneficial for verbally able children with autism. However, no significant treatment effect was reported on structural language skills.

It is important to demonstrate the effectiveness of interventions that speech and language therapists implement with children with autism and explore the use of these strategies. Some of the techniques included in the following sections are aimed at and used with young non-verbal children. Children with poor verbal imitation abilities make the best candidates for augmentative and/or alternative systems of communication (AAC) support (National Research Council, 2001). A large body of research concentrates on the youngest and minimally verbal children and it is important to review these studies here in order to conceptualize what the evidence

base looks like in the absence of studies exploring groups of wider age and verbal ability range. Not much research has been conducted investigating the outcomes of usual speech and language therapy practice (not a specific SLT technique), especially compared to other genres of treatment, like occupational therapy or psychotherapy. One of the aims of this thesis is to look into conventional speech and language therapy practice along with other therapy contexts and investigate how these associate with the pattern of developmental change of children with autism. As already mentioned some more specifically defined techniques are also used in speech and language therapy practice and these will now be discussed in turn.

4.2.1 The Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS) is a visually based communication system used extensively with children who have language deficits due to a variety of disabilities and disorders, including autism spectrum disorders. PECS is based on behavioural methods and uses symbols and pictures to help children develop their speech and communication skills. The six phases in the PECS system are - Phase 1: How to Communicate; Phase 2: Distance and Persistence; Phase 3: Picture Discrimination; Phase 4: Sentence Structure, and Attributes and Language Expansion; Phase 5: Answering Questions; and Phase 6: Commenting (Bondy & Frost, 1994). The effect of the Picture Exchange Communication System (PECS) in autism has been the focus of nineteen studies since 2000 as shown in table 12.

Flippin et al (2010) conducted a meta-analysis in order to assess the effectiveness of PECS. Eight single-subject studies (18 participants) and 3 group studies (95 PECS participants, 65 in other intervention/control) were included. As mentioned by the researchers the quality of scientific rigor was assessed and used as

an inclusion criterion in computation of effect sizes. The results of their study indicated that there was an average effect for advancing the communication skills and a slight effect for speech outcomes. The results that concerned the development of the speech of children with autism following PECS varied among the studies that were included in the analysis and it was not fully indicated that PECS increases verbal communication. Similar conclusions in regards to the efficacy of PECS were reached by Sulzer-Azarroff et al (2009). Sulzer-Azarroff et al (2009) carried out a review of thirty-four controlled single-case studies and group experimental reports on PECS and it was reported that PECS has enabled individuals with autism to express themselves more easily and has improved their communication skills. Most of the participants in the included studies acquired extensive functional vocabularies but did not acquire speech. Furthermore, a meta-analysis (Tincani & Devis, 2010) of sixteen studies on PECS showed that the use of PECS contributes to the promotion of functional communication for children with autism and other disabilities. These studies used single-participant designs and reported quantitative data for picture exchange and/or vocalizations. The studies included in the Tincani & Devis (2010) meta-analysis showed that PECS produced moderate improvements in communication as measured by increased picture exchange during intervention compared to baseline.

A small number of studies include naturalistic or quasi-naturalistic measures of communication (e.g. Gordon et al, 2011). Gordon et al (2011) aimed to examine the form and function of spontaneous communication and outcome predictors in nonverbal children with autism following classroom-based PECS. In this randomized controlled trial the sample from a previous study by Howlin et al (2007) was used. Eighty-four children participated in the study. It was a community-based study that included autistic children aged 4-11 years with little or no functional language, with

no sensory impairment who had not used PECS beyond Phase 1. The PECS training appeared to increase spontaneous requesting for objects or help but not spontaneous requesting for social routine or commenting. Overall, PECS seemed to improve children's spontaneous communication for instrumental requesting using pictures, speech, or both of them merged. These findings lend weight to other studies focusing on PECS (Yoder & Stone, 2006).

In addition to investigating the developmental associations with language described earlier, Yoder and Stone (2006) and Yoder & Lieberman (2010) also explored interventions for young people with autism. Yoder & Stone (2006) conducted a randomized group experiment of 36 children with autism to compare the efficacy of two communication interventions, the Responsive Education and Prelinguistic Milieu Teaching (RPMT) and the Picture Exchange Communication System (PECS).

The Yoder & Stone (2006) study measured the initiation of joint attention before treatment as potential predictor of differential response to treatment. Initial rates of joint attention predicted whether a child gained more from either PECS or RPMT. According to the results, the RPMT was more successful in facilitating initiating joint attention and object exchange turns for children that began treatment with at least some initiating joint attention. On the other hand, the PECS proved to have a superior effect to the RPMT in children who began the treatment with initially lower frequencies of joint attention, which means that the less able children benefited more from PECS.

The two social-communication interventions addressed by Yoder and Stone (2006) were examined further by Yoder & Lieberman (2010), who found that post-treatment measurement of the number of picture exchanges favoured the PECS

intervention. These findings were interpreted as support for the hypothesis that the PECS curriculum can successfully teach a generalized method of coordinating attention without requiring eye contact, to children with ASD. The validity of the results in both studies is strengthened by the use of random assignment in order to assign children to treatments but the fact that the examiners conducting the pre- and post-assessments were also the primary data coders and could not be kept blind to the children's treatment assignment may have influenced the results. The finding of Yoder & Stone (2006) that the less able children benefited more from PECS was not reflected in the Gordon et al (2011) study discussed earlier. It should be taken into consideration though that in the Gordon et al (2011) study the children had severe autism symptoms and were more delayed with regard to their verbal and non-verbal skills. Thus as a group, the children in the latter sample were less able than Yoder and Stone's sample.

In a similar study, Schreibman & Stahmer (2013) conducted a systematic randomly controlled comparison of Pivotal Response Training (PRT) that uses verbal methods to teach communication and PECS that uses pictorial methods. However, their findings differed from the two previous studies (Yoder & Stone, 2006; Yoder & Lieberman, 2010) because their results demonstrated that neither of the two methods was found to be superior to the other and children in both groups showed an increase in their language skills. A possible explanation to the reason why different results were reached is that the children's characteristics varied among the studies (Yoder & Stone, 2006; Yoder & Lieberman, 2010 and Schreibman & Stahmer, 2013) and that they utilized different assessment measures.

The effects of PECS implementation on communication and restricted repetitive stereotype behaviours of children with autism were examined by Magiati &

Howlin (2003). Thirty-four children with autism participated in the study but no control group was utilized. PECS was implemented to the children for the first time at school but it should be noted that seven of them had already been trained in the past. The assessment data were collected two months before treatment and every two months for six months. The results showed that overall there was an improvement in the children's communication level. More specifically significant gains in the use of signs, single words and communication skills were identified. A significant decrease of negative behaviours was also indicated. Nonetheless, as mentioned by the authors the lack of control group makes it difficult to conclude that the improvements were solely caused by PECS.

Another study that reinforces the idea that PECS can be used as a functional means of communication was carried out by Carr and Felce (2007). Carr and Felce (2007) conducted a study using PECS in a classroom with a teacher and classroom aides. The participants consisted of 17 children in the control group who did not receive any additional treatment other than what they were already receiving and 24 children comprised the group using PECS who had 15 hours of training and then PECS use was moved to the classroom in order to use with teachers and aides. The results demonstrated an increase in communication attempts with classroom staff from the children who received PECS training. However, as noted by the authors, since both the researcher and teachers provided PECS instruction, the researcher's or the teachers' training could be responsible for the increase in communication. Also attempting to assess the use of PECS, Lerna et al (2014) focused on the long-term effectiveness of PECS and their findings were consistent with previous findings since they demonstrated that PECS training helps improve children's social-communicative skills.

As it was mentioned earlier Carr & Felce (2007) and Yoder & Stone (2006) demonstrated the efficacy of PECS in improving children's communicative functions and initiating/requesting behaviours. Similar findings were reached by other single-subject studies (Anderson et al, 2007; Charlop-Christy et al, 2002; Ganz & Simpson, 2004; Greenberg et al, 2013; Jurgen et al, 2009; Kravits et al, 2002 and Tincani et al, 2006) that provided further support for the association between PECS and increases in speech development. Charlop-Christy et al (2002) conducted a multiple baseline design across participants in order to explore the effect of PECS in the areas of speech, social-communicative behaviour, and problem behaviour in free-play and academic settings. After observing the progress of the three children who participated in the study, the results showed that all children benefited from the PECS use in a short time; their speech was increased along with their social-communicative behaviours and the problems in their behaviour decreased. The sample size of the previous study is similar with the one of the Ganz and Simpson (2004) study who also investigated the effects of PECS and the relationship between PECS and speech production. Only three children with autism were included in this study as well. As seen in the Ganz and Simpson (2004) study the participants also gained from PECS and increases in average intelligible words spoken per trial were noted. However, no clear relationship between changes in spoken words and non-word vocalizations was identified and the lack of baseline data limits the interpretation of the findings.

The use of PECS on the spontaneous communication skills of a six year old with autism across her home and school was assessed by Kravits et al (2002). Their results demonstrated increases in spontaneous language and verbalizations. Tincani et al (2006) explored the effects of PECS on requesting and speech development of three children with autism. Tincani et al (2006) measured words and word approximations

that came up during the PECS training and their findings are consistent with previous studies that support the use of PECS to promote requesting and speech development (e.g. Charlop-Christy et al, 2002; Ganz & Simpson, 2004; Kravits et al, 2002; Magiati & Howlin, 2003; Yoder & Stone, 2006). However, the generalization of findings of the Tincani et al (2006) study should be considered with caution since a full analysis of the levels of the participants' communications skills prior the intervention was not included.

Increases in the spoken vocabulary of one child with autism following PECS were also demonstrated in a study by Jurgen et al (2009). In the Anderson et al (2007) study one child with autism was taught functional language using PECS and the results also indicated that it is important to take into account the child's characteristics. A recent single subject design study by Greenberg (2013) provides support for the use of PECS with less able nonverbal children. Greenberg et al (2013) included four children in their study and based on their findings there was an increase in most of the participants' vocalizations. It should be taken into account that most of the participants in the previous studies (Anderson et al, 2007; Ganz & Simpson, 2004; Jurgens et al, 2009; Kravits et al, 2002; Magiati & Howlin, 2003) whose speech improved after or during the training in PECS were also able to imitate words before the intervention but in the Greenberg et al (2003) study it was indicated that PECS can benefit children with limited verbal abilities as well. Nonetheless, the small sample sizes along with the different assessment measures and methods across studies that assess the use of PECS to encourage speech development limit conclusions that can be drawn about its effectiveness.

A few studies have contradicted the findings of previous studies (e.g. Charlope-Christy et al, 2002; Ganz & Simpson, 2004; Gordon et al, 2011; Sulzer-

Azarroff et al, 2009; Yoder & Stone, 2006 and Yoder & Lieberman, 2010). Ganz et al (2010) recruited two children with autism, who had not gained functional communication skills after using the PECS. The initial plan was to use a multiple baseline design across participants to investigate the use of speech, but because the participants made very little progress in PECS and verbal modelling the data was presented as in a case study. According to the authors the participants of the study had multiple disabilities and health issues that prevented them from mastering PECS. In a retrospective study by Pasco & Tohill (2010), the authors explored which children make more progress using PECS. Twenty-three children with autism who were 5 or 6 years old and non-verbal participated in the study. The results of the study showed that children with a developmental age below 16 months were unable to master PECS level III. However, children of 5 and 6 years of age who are below this developmental age are more likely to depend on PECS and for a longer period than others. Several limitations in both studies weaken the validity of the results. In the Ganz et al (2010) study the sample was very small, no experimental control was demonstrated and due to the fact that the study was conducted only during the summer the participants were not available afterwards to try a modified version of PECS or another technique in order to compare. Therefore, we do not know whether or not the children would have responded to modified PECS instruction or what types of modification would benefit them. In the Pasco & Tohill (2010) study the participants were not randomly assigned or selected prospectively and the outcome PECS level assessments were partially conducted by the second author, who was not blinded to the purpose of the study. Also, the PECS was implemented by the staff in the school and no further information about the implementation is provided to us.

4.2.2 Summary

Considering the evidence with the highest confidence (Sackett et al, 1996), it is demonstrated in this section that the PECS approach can promote communication in children with autism. The evidence though that PECS can increase speech production in children with autism is not as strong, so further research is needed to establish the efficacy of this approach in improving speech development and promoting more advanced communications skills. In summary, two meta-analyses (Flippin et al, 2010; Tincani & Devis, 2010) and a literature review (Sulzer-Azarroff et al, 2009) demonstrated an average effect of PECS for advancing the communication skills of children with autism. The benefits of PECS in the area of communication were also portrayed in four randomized controlled trials (Gordon et al, 2011; Yoder and Stone, 2006; Yoder & Lieberman, 2010 and Schreibman & Stahmer, 2013) that explored the use of PECS with children with autism. Additionally, two studies (Ganz et al, 2010; Pasco & Tohill, 2010) contradicted the effectiveness of the use of PECS for autistic children.

Table 12. The Picture Exchange Communication System (PECS)

Study	Country	Sample	Type of treatment	Outcome Measures	- Key findings
Flipin et al (2010) Meta-analysis Level I evidence	USA	76 studies on PECS	PECS	Systematic review of the literature on PECS written between 1994-2009	- Average effect for advancing the communication skills and a slight effect for speech outcomes - It was not fully indicated that PECS increases verbal communication
Gordon et al (2011) RCT Level I evidence	UK	84 non-verbal children with autism aged 4-10 y	PECS vs eclectic approach	Videotaped observation	- Increase in spontaneous requesting for objects or help/ spontaneous communication for instrumental requesting - Spontaneous requesting for social routine or commenting did not increase
Schreibman & Stahmer (2013) RCT Level I evidence	USA	39 children with autism aged between 2-4	PECS vs Pivotal Response Training (PRT)	MSEL, EOWPVT, CDI,VABS	- Neither of the two methods was found to be superior to the other - Children in both groups showed an increase in their language skills
Sulzer-Azarroff et al (2009) Review Level I evidence	USA	34 peer reviewed published reports on PECS	PECS	Systematic review of the literature on PECS written between 1994-2008	- PECS has enabled individuals with autism to express themselves more easily and has improved their communication skills
Tincani & Devis (2010)	USA	16 single-participant studies	PECS	Review of single-participant	- Use of PECS contributes to the promotion of functional communication for children with autism

Meta-analysis Level I evidence				studies between 2002-2009	and other disabilities - PECS is supported as an evidence-based communication intervention[8]
Yoder and Stone (2006) RCT Level I evidence	USA	36 children with autism (mean age=32 mo); 19 assigned to PECS and 17 to RPMT	PECS vs Responsive Education and Prelinguistic Milieu Teaching (RPMT)	ADOS, ESCS	- RPMT increased object exchange turns more - Children with higher joint attention benefitted more from RPMT and children with little to no joint attention benefitted more from PECS
Yoder & Lieberman (2010) RCT Level I evidence	USA	36 children with autism (mean age=32 mo); 19 assigned to PECS and 17 to RPMT	PECS vs Responsive Education and Prelinguistic Milieu Teaching (RPMT)	ESCS	- PECS increased the number of picture exchanges more than RPMT
Carr & Felce (2007) Group Comparison Level II evidence	UK	17 children in the control group received treatment as usual and 24 children received PECS; aged 3-7y	PECS vs treatment as usual	VABS,PLS-3	- Increase in communication attempts with classroom staff from the children who received PECS
Lerna et al (2014) Follow-up study Level II evidence	Italy	PECS group (n=7; mean age: 71.1 mo) Language group (n=7, mean age: 66.2 mo)	PECS Conventional Language Therapy	GMDS,ADOS,VABS,videotaped records of free play sessions	- Long-term improvements in children's social-communicative skills after PECS
Magiati & Howlin (2003) Pilot evaluation study Level III evidence	UK	34 children with ASD aged 5-10 y	PECS	ASQ,ADI-R, child's general characteristics questionnaire, VABS, ATEC, Communication Checklist	- Improvement in communication level - Gains in the use of signs, single words and communication skills - Significant decrease of negative behaviours

[8] A complete list of the full names of assessment measures included in this chapter is provided in Appendix VI

Pasco & Tohill (2010) Retrospective Level III evidence	UK	23 children with autism aged 5 or 6 years old and non-verbal	PECS	PEP-R	- Children with a developmental age below 16 mo were unable to master PECS level III - Children of 5 and 6 y who are below the developmental age of 16 mo are more likely to depend on PECS and for a longer period than others

4.2.3 Functional Communication Training (FCT) and Speech Generating Devices (SGD)

Functional communication training (FCT) is established in the area of behaviour analysis but it is often used by speech and language therapists to target deficits in communication skills. This type of intervention has been used to replace challenging behaviour with more appropriate forms of communication (Durand, 1993; Durand & Carr, 1991). Typically, a functional assessment is conducted to identify the communicative function of the problem behaviour. The efficacy of the FCT has been supported by research studies and found to be effective for replacing problematic behaviours, like non-contextual speech (Franco et al, 2009; Wu et al, 2011).

Keen et al (2001) investigated the effectiveness of a variation of Functional Communication Training (FCT), aiming to replace pre-linguistic behaviours with more recognizable and symbolic forms of communication. The intervention was teacher implemented and four children with autism participated in the study. Teachers used the second edition of the Receptive-Expressive Emergent Language Scale (REEL-2; Bzoch & League, 1991) to assess language ability, the TARC Assessment System (Sailor & Mix, 1975) to assess self-help, motor, communication, and social skills, the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1994) to assess the children's severity of emotional and behavioural disturbance and the Inventory of Potential Communicative Acts (IPCA; Sigafoos et al., 2000), which is an interview schedule designed to identify pre-linguistic behaviours of children with developmental and physical disabilities who have severe communication impairment. The results suggested that all children experienced an increase in replacement behaviour and a corresponding decrease in pre-linguistic behaviour across a range of

communicative functions during intervention.

According to Goldin et al (2014) deficits in the area of communication are quite common with children with autism and severe impairment is often linked with negative behaviours like aggression and acts of self-harm (Matson & Lovullo, 2008). Various interventions focus on the improvement of the communication skills and on the production of a feasible augmentative and alternative communication system (Waddington et al, 2014). This kind of system offers children with severe communication deficits the chance to communicate via an alternative method. As reported by Mirenda et al (2009) alternative and augmentative communication systems (AAC) are divided into aided and unaided ones. The unaided systems include the use of manual signs and gestures. The aided systems involve external equipment (van der Meer et al, 2011) like speech-generating devices. Speech-generating devices (SGD) are programmable digital devices that provide voice output in the form of digitized or synthesized speech when activated (Trottier et al, 2011). This specific approach was not used with any of the children included in this thesis but still it is useful to get an idea of the research surrounding interventions that include the use of SGDs for children with autism, since there are many children in the autism spectrum with severe communication impairment.

A systematic review of communication intervention studies that involved the use of speech-generating devices (SGD) for children with autism, conducted by Van der Meer & Rispoli (2010), concluded that SGDs can be beneficial for this population. The authors identified twenty-three studies and in regards to the quality of evidence, the studies reviewed implemented single-participant designs to evaluate the effects of the SGD intervention on communication and achieved clear intervention results, where positive outcomes and certainty of evidence were both high (87% and

78%, respectively). Thus, in most of the studies the communication skills that were targeted, e.g. to teach a child to request, improved for all participants.

There appear to have been no large-scale randomized controlled trials investigating the effectiveness of SGDs for children with autism. Allen et al, (2015); Boesch et al (2013); Flores et al (2012); Thundberg et al (2009); Trottier et al (2011) and van der Meer & Rispoli (2010) investigated the use of SGDs aiming to promote communication skills in children with autism. Allen et al (2015) investigated whether it is easier for children with autism to obtain vocabulary and object knowledge from iPads or picture books. Sixteen children with autism and limited language skills participated in the study and the researchers found that the medium of presentation did not influence the children's symbolic understanding of word-picture-object relations. Boesch et al (2013) and Flores et al (2012) compared the efficacy of two AAC methods, PECS and a SGD, in improving social-communicative function and speech production for three children with autism. Boesch et al (2013) found that there were no clear distinctions between the two mediums. However, Flores et al (2012) reported that the gains of alternative communication methods vary across children in the autism spectrum (Lorah et al, 2013).

Thundberg et al (2009) and Trottier et al (2011) also investigated the effectiveness of speech-generating devices (SGDs) in a small sample of children with autism. The results were positive in both studies; in the Thundberg et al (2009) study an increased level of communication effectiveness was noted in all children and in the Trottier et al (2011) an increase in total appropriate communicative acts (CAs) was found. A number of recent studies focus on the use of iPad and iPod touch as SGDs for children with autism who find it difficult to communicate (Achmadi et al, 2012; Flores et al, 2012; Kagohara et al, 2010; Lorah et al, 2013; van der Meer et al, 2013

and Waddington et al, 2014). These studies suggest that this form of speech generating system helps children with autism with their instrumental and social communicative functions.

However, the results of most of the studies included in this section should be considered with caution due to the small sample sizes, (e.g. 1-4 participants) which limit the generalization of the findings, especially if we take into consideration the diversity in the symptoms children with autism present with. Additionally, it should be taken into consideration that often SGDs are used to teach children with autism, simple communications skills, e.g. a simple requesting response, and they might not target more advanced communications skills.

4.2.4 Summary

An overview of studies surrounding the use of communication interventions like FCT and SGDs for children with autism show that more large-scale randomized control trials evaluating these approaches are needed. Nonetheless, single-participant studies rated as moderate level evidence (Sackett et al, 1996); show that the specific interventions can promote functional communication in children with autism. One related review covering the use of SGDs for children with autism reported the promise of SGD technology for enabling functional but in general basic communication skills. Future research could also focus on the suitability of these techniques based on the initial communication skills of the child.

4.2.5 The Natural Language Paradigm (NLP) and other parent implemented interventions

The Natural Language Paradigm (NLP) also called Pivotal Response Training (PRT) is an intervention procedure that is equivalent to the manner in which typically developing children acquire language (Koegel et al, 1987). NLP/PRT uses techniques aiming to provide the required circumstances in order to increase the chances of children to use language. The training is implemented during play activities and adults try to offer as many opportunities as possible to the children to promote their speech abilities. Every attempt by the child to verbalize is reinforced. Also, the therapists model various words and phrases and they try to exchange toys with the children in a quick manner (Laski et al, 1988). The Natural Language Paradigm (NLP) approach, sometimes can be parent or teacher implemented. Other parent implemented interventions are also reviewed here (e.g. Green et al, 2010).

The effect of the Natural Language Paradigm (NLP) also known as Pivotal Response Training (PRT) was the focus of three small-scale studies (Gillett & LeBlanc, 2006; Koegel et al, 2009 and Seiverling et al, 2009). In the Gillett & LeBlanc (2006) study, three parents of children with autism were trained to implement the Natural Language Paradigm (NLP). In this study, increases in the overall rate of vocalizations were observed for all three children and advances in play were observed in the two children who began the study with limited appropriate play. Improvement in the spontaneous language of the participants was evident as well. A similar finding regarding increases in child vocalizations was found in the study by Seiverling et al (2009). Koegel et al (2009) examined the differences in child initiated social behaviours within two experimental conditions: the non-embedded reinforce condition and the embedded social condition. Both conditions used a Pivotal

Response Treatment paradigm to set up and reinforce language opportunities. The results showed that embedding social interactions into the reinforcers led to increases in child-initiated social engagement during communication along with improvements in non-verbal dyadic orienting and in general child affect. However, the findings in all three studies (Gillett & LeBlanc, 2006; Koegel et al, 2009 and Seiverling et al, 2009) could be considered limited as they used very small samples (three children).

A recent study by Green et al (2010) explored a parent-implemented method called the parent-mediated communication-focused treatment (PACT). This type of intervention targets the child's communication by promoting the parents' sensitivity and responsiveness to them with the use of video feedback. Green et al (2010) conducted a large, randomised controlled trial with 152 participants; 77 were randomised in a PACT group that also had treatment as usual at three specialist centres in the UK and 75 in a group that only had treatment as usual. The families attended biweekly 2h clinic sessions for 6m followed by monthly booster sessions for 6m. Also, the families were asked to do 30 minutes of home practice every day. The exact dosage of treatment as usual that the participants had at their local services is not mentioned. The ADOS-G was the primary outcome measure used to assess the severity of autism and video recordings of parent-child interaction during naturalistic play were also rated. The children's language and social communication were assessed using the Preschool Language Scales and the parents completed the MacArthur Communicative Development Inventory and the Communication and Symbolic Behaviour Scales Developmental Profile. Additionally, the Vineland Adaptive Behaviour Scale was used to assess the adaptive functioning of the children in school. No significant differences were found between the two groups following intervention. Nonetheless, it was noted that the intervention helped improve the

parent-child social communication, because the parent ratings of language and social communication were higher in the PACT group.

An earlier pilot study by Aldred et al (2004) also explored the effectiveness of PACT in children with autism. In total twenty-eight children with autism were recruited and were randomly assigned to this type of treatment and routine care. The children were assessed 12 months after the implementation of the intervention, using standardised instruments. Unlike the study by Green et al (2010) the results showed significant improvements in the areas of reciprocal social interaction and in expressive language.

A smaller sample of eleven children was used in a pilot trial by Tamanaha & Perissinotto (2011) and two types of intervention were compared: a) a direct speech and language therapy intervention (Therapy Group-TG), which was implemented by the speech and language therapist and consisted of planning and implementing strategies focused on the abilities and disabilities of each child. The parents were always involved in the individual sessions and participated either by watching the interventions, or by dealing with the child; b) an indirect speech therapy intervention (Orientation Group-OG), which constituted the planning of strategies performed by the speech and language therapist, but these were implemented by the families. Children were assessed on a battery of standardized tests and the findings showed more positive gains in the Therapy Group, which demonstrates the positive effect of collaboration between family and therapist. Nonetheless the small sample size limited the strength of the results.

Similarly, Chandler et al (2002) studied ten children with autism, aged 1:10 to 2:9 years old at assessment, who participated in a parent-implemented intervention.

The intervention was based on the hypothesis that the pragmatics of language are the precursors of speech itself and enable both communication and relationship between child and parents. The programme included home visits, modelling, workshops and written information, with parents as 'therapists' in naturally occurring situations and lasted for 18 months. Evaluative interviews were carried out with parents 6 months and 12 months into the intervention, and also 6 months post-intervention. In addition, Pre-verbal Communication Checklists and Pragmatics Profiles were completed for each child at 6 monthly intervals, by parents in discussion with the research psychologist. Also, the children's progress was monitored through video records, observational notes and diaries kept by parents. The results showed that all children made significant progress in social interaction and expressive communication, including gestural and verbal communication. However, the lack of control group and the fact that the parents rated the progress of their own children, might have biased the results, and thus limit any conclusive statements.

In a retrospective study by Seung et al (2006) the efficacy of a parent-implemented intervention on the communicative outcomes of eight children (aged 4-7 years) with autism was explored. The results demonstrated a decrease in the ratio of parent to child utterances and an increase in the use of imitation by the parents and the number of single words and different words produced by the child. Therefore, the efficacy of parent training that focuses on the promotion of social reciprocity is suggested. More robust evidence was provided by a randomized controlled trial by Drew et al (2002). In this study parents of children with autism were also trained to provide treatment aiming to improve their children's language and communication skills. Parents were randomized to the parent-training group (n=12) or to local services only (n=12). After 12 months the results suggested that the language of the

children (mean age: 35 months) in the parent-training group was more advanced than the ones in the local services group. However, no significant differences were found between the two groups in regards to non-verbal IQ, symptom severity and parents' self-reported stress.

Girolametto et al (2007) used a case study approach in order to investigate the effect of a social interactive model of language intervention, entitled the More Than Words Program: The Hanen Program for Parents of Children with Autism Spectrum Disorders (Sussman, 1999). Three families of children with autism were assessed on tests that measured the parental responsiveness, the concomitant changes in children's vocabulary and social interaction behaviours. The findings of the Girolametto et al (2007) study showed increases in communicative acts and social interaction episodes.

4.2.6 Summary

Participation of parents of children with autism becomes more and more common in various intervention programs, yet there is not enough rigorous research relating to the best practices. Small-scale studies support the use of NLP/PRT and PACT to promote communication skills in children with autism. In small studies though the likelihood that a statistically significant result reflects a true effect is reduced. Two studies (Aldred et al, 2004; Drew et al, 2002) rated as strong level I evidence (Sackett et al, 1996), supported the use of parent training interventions to advance children's language and social skills. Additionally, it should be highlighted that a large randomized controlled trial conducted by Green et al (2010) did not demonstrate the effectiveness of PACT with autistic children but highlighted its contribution to advancing parent-child social communication.

4.2.7 Naturalistic intervention techniques

Milieu Teaching was the focus of three studies (Ingersoll, 2011; Kasari et al, 2008 and Yoder & Stone, 2006) and the offer of choices in language interventions was the focus of one study (Carter, 2001).

Milieu teaching is a naturalistic approach to teaching language in a child's environment (Goldstein, 2002). Paul & Sutherland (2005) suggest that milieu teaching consists of the following: a) the training and the teaching take place in a naturalistic environment and not in a specific room for therapy; b) the aim is for the therapeutic activities to become a part of the individual's daily routine and not restricted only to therapy time; c) the children's favourite activities and toys are included in the environment in order to promote self reinforcing; d) spontaneous communication is encouraged by using expectant waiting (facial expressions/gaze) instead of prompting; e) the children's gestures or other indication of interest towards an object or an activity are considered as an initiation; f) adults try to expand these initiations by providing various cues and prompts and when these responses are expanded the children are rewarded with their preferred object or activity (as cited in Myles et al, 2007). This strategy is considered important for children with autism, many of whom do not use the words they understand to communicate (Yoder & McDuffie, 2006). Extended research has demonstrated the effectiveness of milieu teaching methods and their use to increase communication skills (Goldstein, 2002; Kasari et al, 2006 and Yoder & Stone, 2006).

Kasari et al (2008) explored the link between milieu teaching and language acquisition. The authors conducted a randomised controlled trial, which considered the relevance of joint attention and symbolic play in 58 preschool children with autism and correlated this to language acquisition measured after 12 months. A joint

attention intervention was used, based on the developmental principles of milieu teaching. This study used the data from follow up assessments of children from an earlier randomized controlled trial (RCT) (Kasari et al., 2006) and the participants were randomised into one of three study arms namely joint attention intervention, a symbolic play intervention, and a control group. Findings suggested that the interventions that focused on joint attention and symbolic play skills had significant effects on language acquisition. It is noteworthy that in this study for the children beginning treatment with the lowest language levels, the joint attention intervention improved the language outcome significantly more than the symbolic play or control interventions. Therefore, this suggests that early intervention targeting joint attention appears to benefit the language development of children with autism. However, the above finding might lead to the assumption that there was more room for improvement in these children, since they had the lowest language levels.

Two single-subject studies (Ingersoll, 2011 and Carter, 2001) examined the effect of language interventions on autism. Ingersoll (2011) compared the effects of responsive interaction, milieu teaching, and a combined intervention on the type and communicative function of expressive language in pre-schoolers with autism, using a randomized alternating treatments design. The study by Ingersoll (2011) reaches similar conclusions to Kasari et al (2008) and supports the idea that naturalistic interventions, such as Milieu Teaching, help the language levels of children with autism improve. The results of this study demonstrated that Milieu teaching led to more overall language, prompted language, and requests than the responsive interaction approach. Responsive interaction helped children make more comments than milieu teaching. The combined intervention was similar to milieu teaching for prompted language and requests and to responsive interaction for child comments.

The small number of treatment sessions per condition might have affected the interpretation of the results, but it is interesting that very small dosage of intervention may be effective.

Carter (2001) aimed to determine whether providing choice opportunities[9] in language interventions during disruptive periods of behaviour improved language acquisition skills in those with autism. The results showed that the disruptive behaviour of the children was reduced when they were offered choice decisions in language interventions, which incorporated interactive play. All the participants showed decreased levels of disruptive behaviours, increased play initiations and higher levels of actions to maintain play in the Choice conditions when compared with the No Choice conditions. Disruptive behaviour was measured as the number of occurrences of the therapist redirecting the child to the task by verbal instructions and it was scored during the intervention sessions and from the videotapes of all sessions.

4.2.8 Summary

The results of the studies included in this section indicated that incorporating a naturalistic approach into the interventions of children with autism might have a positive effect on the children's social-communicative behaviour. One of the methods used to consolidate situational interests into learning opportunities for children with autism was child choice making among different materials or activities. In summary, there is considerable promise in the naturalistic approaches and their efficacy has been demonstrated in individual treatment and group interventions. However, the level of evidence and study quality were variable with the majority of

[9] Choice in language intervention has characteristically referred to following the child's lead (i.e., attention, interest; Yoder et al, 1999) and using child preferred or child selected materials, topics and toys in communicative interactions (Koegel et al, 1999)

studies identified being lower level evidence. The study with the highest rating (Kasari et al, 2008) demonstrated improvements in autistic children's language development following milieu teaching. More studies are needed though, including a larger number of children and more group design studies that avoid the possibility of carryover effects.

4.2.9 Direct Instruction and Narrative Based Language Interventions

Direct Instruction (DI) is a method of instruction that is explicit, intensive, and teacher-directed and was developed by Siegfried Engelmann and his colleagues (Adams, 1997). The DI is based on the basic skills model and the technique used focuses on building up the basic skills needed and gradually advancing to upper level thinking skills. A lot of practice is required in order to achieve mastery of each skill. This approach uses certain methods to teach children progressively complicated skills and strategies. Additionally, DI has been used with children with a variety of abilities, including autism (Flores and Ganz, 2007).

According to Swanson et al (2005) Narrative Based Language Intervention (NBLI) is a language intervention approach that combines naturalistic activities (such as story telling) with skill-based activities to address children's language and communication goals. The aim of NBLI is to help children generate narratives and via the development of these skills they target the expansion of their language skills at the same time.

Dodd et al (2011) investigated the use of a narrative-based language intervention program for teaching perspective-taking skills to students with autism. Eighteen participants were randomly assigned to one of two treatment groups: the narrative-based intervention group that focused on teaching perspective-taking (PTI)

and the traditional narrative-based language intervention group (NBLI) that focused on story elements and semantics. The results showed that the students who received the PTI showed more positive gains in their ability to retell a story from the perspective of different characters compared to those who participated in the NBLI. However, there are a few methodological limitations in the Dodd et al (2011) study. Researcher bias limited any definite conclusions as the first two investigators of the study were the data collectors as well as the clinicians who provided the interventions and they might have influenced the whole process. Also, another limitation in the Dodd et al (2011) study may be related to the pre- and post-intervention data collection procedures, since they were collected in a single session. According to the authors irregularity is noted among children with autism, which is difficult to be evaluated during a single session.

The aim of a study by Ganz & Flores (2014) was to identify whether the DI would be more effective than an evidence-based behavioural practice called Discrete Trial Teaching (DTT) approach, which also uses an instructional method. The results of this study suggested more improvement in the DI group compared to the DTT one. A more recent study by Shillinsburg et al (2015) extends the line of research in the area of DI, by demonstrating the effectiveness of the intervention in increasing children's language skills. However, both studies were limited in size and time. In the Ganz & Flores (2014) study 13 participants were recruited and the intervention lasted for four weeks and in the Shillinsburg et al (2015) study the 18 children who participated received a total of 36 to 40 hours of treatment over a 3 month period and the follow-up was up to 6-8 months. It would be interesting though to assess the long-term impact of this intervention and explore the stability of the improvements of these children for a longer period of time.

A study by Ganz & Flores (2009) following a single case study design also investigated the effect of a language intervention implemented with three students with autism. The results of the study demonstrated the effectiveness of the DI program with regard to the students' oral language skills. Nonetheless the efficacy of DI does not rule out the effects of other interventions since it was not compared with other methods.

4.2.10 Summary

In summary, based on the evidence with the highest confidence, the positive gains of a narrative-based language intervention program for teaching perspective-taking skills to students with autism were presented by Dodd et al (2011). The remaining lower level evidence studies (Ganz & Flores, 2009; Ganz & Flores, 2014; Shillinsburg et al, 2015) demonstrated the positive effect of the Direct Instruction (DI) language program. More research is needed though to determine the overall impact and implications of these programs. Future research could include a larger number of children; control groups and various participants functioning at different levels to demonstrate more clearly for which children these approaches are appropriate.

4.2.11 Denver Model, PROMPT, ALM methods

The Denver Model (Rogers et al, 2000) is a developmental approach to early autism treatment that delivers a specified developmental curriculum (individualized for each child based on current abilities) using a combination of empirically supported teaching techniques to attain specific developmental outcomes. The Denver Model aims to build upon the skills the child with autism has already gained and includes several teaching elements: shaping of natural gestures followed by conventional

gestures; teaching motor-imitation skills related to language; and teaching the meaning and importance of speech. This model uses the tools of functional behavioural analysis; communication training; positive teaching of alternative, more conventional behaviours; and redirection to provide new behavioural strategies by which the child can achieve their goals (Roberts, 2004).

Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT) is a technique that incorporates neuromotor principles, kinesthetic and proprioceptive information, as well as auditory and visual information to provide feedback to the speech system, in order for an individual to produce clear, functional speech. The PROMPT clinician provides input to all areas of oral motor system by using touch, pressure, specific placements, as well as creating auditory and visual awareness. This helps an individual achieve controlled, functional speech.

Aided Language Modeling (ALM) consists of engaging the child in interactive play activities and providing models of use of augmentative and alternative communication symbols during play. The ALM intervention consists of the following elements: engaging the child in interactive play activities and providing models of use of the Alternative Augmentative Communication (AAC) symbols during this naturalistic play (Drager, 2006).

The Denver model and PROMPT were examined in a single subject design study by Rogers et al (2006). Ten young, nonverbal children with autism were matched in pairs and randomized to treatment. A battery of standardized tests focused on cognitive and language functioning, adaptive behaviour and autism symptoms pre- and post-treatment. Additionally, parents were interviewed about the child's autism symptoms, adaptive behaviours and use of words and gestures. The results demonstrated that eight of the ten participants developed vocabularies of at least

multiple single words used routinely during therapy sessions; four of these children developed phrase speech, two of whom generated and used phrase speech spontaneously and in multiple situations. It is noted though that the eight children's speech production was still limited at the end of the treatment and that some children were involved in other treatments as well during the study, so it is difficult to predict how this affected the results.

Two single-subject design studies (Bellon-Harn et al, 2007; Drager et al, 2006) investigated the use of language interventions for children with autism and reported positive results. Bellon-Harn et al (2007) presented a case study of an eight-year-old boy with autism for whom prosody became the main focus of intervention. According to the authors, after atypical prosodic behaviours were operationalized, explicit strategies were employed within the context of an interactive approach to address atypical prosody. Following ten sessions it was reported that the number of syllables produced with lengthening and the number of utterances with excessive pausing markedly decreased. However, the lack of experimental control challenges the validity and generalizability of the results, since the positive changes seen in the child might have been due to his maturation or other factors that were not taken into consideration.

A multiple-baseline design across sets of symbol vocabulary was used with two children who had autism by Drager et al (2006). The authors aimed to explore the use of Aided Language Modeling (ALM). The participants of the study were two preschool children with autism who had significantly impaired communication skills. Each child participated in three experimental conditions for each group of vocabulary: baseline, intervention, and maintenance and thirty-seven sessions were conducted

over five months. The results showed increases in the symbol comprehension and symbol production of the children following intervention.

4.2.12 Summary

In summary, the study with the strongest evidence rating conducted by Rogers et al (2006), examined two models of intervention: the Denver Model and the PROMPT; Bellon-Harn et al (2007) presented a case study of a boy with autism for whom prosody became the main focus of intervention and Drager et al (2006) aimed to explore the use of an instructional procedure named Aided Language Modeling (ALM). The results of the studies mentioned above indicated that these interventions led to meaningful linguistic gains.

Table 13. Speech and Language Therapy Techniques

Study	Country	Sample	Type of treatment	Outcome Measures	Key findings
Aldred et al (2004) RCT Level I evidence	UK	28 children with autism (aged 24-71 mo)	Parent-mediated communication-focused treatment (PACT) vs treatment as usual	ADI-R, ADOS, VABS, CDI, PSI, video coding procedure	- Significant improvements in the areas of reciprocal social interaction and in expressive language after receiving PACT
Dodd et al (2011) RCT Level I evidence	USA	18 children with autism aged 9-12	Perspective-taking (PTI) Narrative-based language intervention group (NBLI)	SGM	- Students who received the PTI showed more positive gains in their ability to retell a story from the perspective of different characters -
Drew et al (2002) RCT Level I evidence	UK	parent-training group (n=12) to local services group (n=12), mean age: 23 mo	Parent training intervention vs treatment as usual	CDI, Griffith's Scale of Infant Development, ADI-R, PSI, activity checklist	- Beneficial effect of the parent training on the communicative competence of the children - No significant differences in non-verbal IQ, symptom severity and parents' self-reported stress -
Green et al (2010) RCT Level I evidence	UK	152 children with autism aged 2-4 y	Parent-mediated communication-focused treatment (PACT) vs treatment as usual	ADOS, video rating, PLS, CDI, CSBS-DP, VABS	- No significant differences were found between the two groups following intervention - Improvement in the parent-child social communication.

Kasari et al, 2008 RCT Level I evidence	USA	58 children with autism 3 and 4 y	Milieu-based intervention on JA and symbolic play intervention	ADOS, ADI-R, MSEL, RDLS, ESCS, demographics questionnaire, structured play assessment	- Early intervention targeting joint attention appears to benefit the language development of children with autism - Expressive language gains were greater for both treatment groups compared with the control group
van der Meer & Rispoli (2010) Systematic review Level I evidence	New Zealand	23 single-subject design studies that included the use of Speech-generating device (SGDs)	Speech-generating device (SGD)	Review of single-participant studies on Speech-generating device (SGD) up to 2009	- 86% reported positive results - 78% provided conclusive evidence
Rogers et al (2006) Single-subject Level II evidence	USA	10 nonverbal children aged 20-65 mo with autism matched in pairs and randomized to treatment were assessed pre- and post-treatment	Denver Model PROMPT	ADOS, SCQ, MSEL, VABS, CDI, demographics questionnaire, baseline speech probes	- 8 children developed vocabularies of at least multiple single words used routinely during therapy sessions in both groups - 4 children developed phrase speech, 2 of whom generated and used phrase speech spontaneously and in multiple situations - Speech production of 8 children was still limited at the end of the treatment
Tamanaha & Perissinotto (2011) Clinical trial Level II evidence	Brazil	6 children with autism and 5 with Asperger's, aged 50-120 mo randomized to two groups	Speech and language therapy (direct and indirect intervention)	ABC,SVB	- The combination of direct and indirect intervention contributes to a greater extent to the evolution of children

					- Positive effect of collaboration between family and therapist -
Chandler et al (2002) Pre-posttest Level III evidence	UK	10 children with autism aged 1:10 to 2:9	Individualized programme focused on the pragmatics of language	Pre-verbal Communication Checklist, Pragmatics Profile	- Significant progress in social interaction and expressive communication, including gestural and verbal communication -
Ganz & Flores (2014) Two-grouppre-post test Level III	USA	13 children with autism aged 4-10 y	Direct Instruction (DI) Discrete Trial Teaching (DTT)	Language for Learning	- More improvement in the DI group
Seung et al (2006) Retrospective Level III evidence	USA	8 children with autism aged 4-7 y	Parent training that consisted of two components: a) expectant waiting; and b) imitating with animation	ADI-R, CARS, Systematic Analysis of Language Transcripts	- Decrease in the ratio of parent to child utterances - Increase in the use of imitation by the parents - Increase in the number of single words and different words produced by the children.
Shillinsburg et al (2015) Pre-post test Level III evidence	USA	18 children with an ASD aged 4-12 y	Direct Instruction (DI)	Language for learning tests	- Effective in increasing children's language skills

4.3 Summary

The growing body of research reported above has demonstrated that speech and language treatments are especially promising for children with autism. The field of language interventions is broad and there is a great variety of techniques used to promote the language and communication skills in children with autism. However, the research is subject to methodological constraints. It is also evident that most of the studies are conducted in the US and the UK.

Multiple research designs have contributed to the SLT evidence reported above but a majority of the studies employed a single-subject design. In most of the studies researchers described participants as having autism or used another term e.g. ASD, PDD/NOS or Asperger's, which was mainly confirmed via a formal diagnosis. Although the studies reviewed here incorporated a variety of outcomes the focus was mostly on the outcomes associated with the treatment provided to the child. A variety of language oriented practices were supported by demonstrations of efficacy but they might have employed a very small sample or have insufficient evidence (e.g. Drager et al, 2006). In some of the studies the effectiveness of an intervention was measured under real-world conditions, e.g. the children's parents implemented the treatment (Gillet & Le Blanc, 2006).

Based on this overview of different techniques used in speech and language therapy it can be seen that findings support various practices as effective mediums in order to promote communication for individuals with ASD. For example, the efficacy of several specific techniques has been shown through randomized and single subject design studies. Single subject studies can be useful for illuminating our understanding of the use of these techniques for children with autism but it is difficult to use them for an evaluation of these interventions. It should be taken into consideration that

some of them included some type of control (e.g. Charlop-Christy et al, 2002; Greenberg et al, 2013; Jurgen et al, 2009; Kravits et al, 2002 and Tincani et al, 2006; Ingersoll, 2011; Carter, 2001 and Drager et al, 2006) and these might add to the evidence base for SLT interventions. Nonetheless, the absence of a comparison group limited conclusions in several occasions across the studies (e.g. Anderson et al, 2007; Ganz & Simpson, 2004; Ganz et al, 2010; Jurgen et al, 2009 and Bellon-Harn et al, 2007). Furthermore, although the single participant's data are supportive of the utility of many of these techniques in promoting communication for children with autism, more research with larger samples of participants is needed. Additionally, it should be taken into account that experimental time limitations might have prevented participants in some studies from progressing (e.g. Shillinsburg et al, 2015). Longitudinal studies are critical in autism research because they help us further our understanding of the long-term benefits of various treatments and give us the opportunity to learn more about the manifestation of autism over time.

There are not many studies investigating speech and language therapy that use the randomized controlled design to demonstrate if this type of treatment is effective. However, randomized controlled trials are needed in order to demonstrate if the effects of a certain treatment resulted from the actual intervention or from other factors that were not controlled. When conducting research investigating the effect of a therapy for children with autism there are several practical and methodological difficulties. For example, it is difficult to control for other therapies that the participants might have during the study. This reflects the real-life situation though, since families of children with autism might receive more than one treatment at the same time. Single-subject design studies have provided most of the knowledge on many of the SLT interventions. Such studies often provide detailed information and

document the change in children who receive this type of treatment but it makes it difficult to generalize the findings and more difficult to control for aspects, like maturation or placebo effect. Randomized controlled trials in this field could be scarcer because most researchers are able to access small samples and they cannot find easily a control group.

Several speech and language oriented techniques that seemed to be beneficial for children with autism are discussed in this chapter. For example, naturalistic interventions, such as Milieu Teaching, have been found to help the language levels of children with autism improve and researchers have focused on the positive effect of parent-implemented interventions. A growing body of research also supports the use of augmentative and alternative communication system (AAC) methods for children with autism. More specifically the use of speech-generating devices (SGDs) by children with autism has received support through the years, as seen in section 4.2.3. However, research comparing SGDs to other types of treatment presents with mixed findings. Likewise, based on the strongest evidence provided by the studies focusing on the use of PECS with autistic children, it is indicated that the specific approach can be an especially promising system for enabling more the social-communicative behaviours of children with autism than their verbal skills, as shown in Table 12.

Conclusively, it can be seen in this chapter that whilst specific methods have been compared, there is a lack of evidence simply comparing conventional speech and language therapy practice across disciplines. Research mostly focuses on specific programmes, but speech and language therapists do not necessarily follow these. Therefore, one of the aims of my thesis is to provide information about general speech and language therapy practice. As Farnsworth and Diehl (2003) stated an eclectic selection of the appropriate therapeutic techniques for every child is necessary and

should be adjusted to their unique communication skills. The findings of a study by Roulstone (2015) also support the view that clinicians tend to extract different theories and resources from various programmes in order to form their interventions. Moreover as it was mentioned earlier an overview of AAC methods, e.g. use of SGDs, was included because it is important to contemplate what the evidence suggests in terms of the treatment of non-verbal children. Nevertheless, non-verbal children were not included in the sample of this thesis, only minimally verbal children with autism.

Chapter 5 Psychotherapy

5.1 Introduction

Psychotherapy is a type of intervention that addresses social, emotional and behavioural problems. In the field of psychotherapy there are different approaches. These approaches can be conceived as conceptual views and general statements about the emphasis of the intervention (Kazdin, 2000). Chapter 5 presents an overview of studies exploring the usefulness of psychoanalytic/psychodynamic psychotherapy when working with children with autism. The following sections review the literature on the use of psychoanalytic psychotherapy with children with autism and on the use of the psychodynamic approach. Finally a summary of the findings is provided.

The goal of this review is to provide guidance on the psychoanalytic/psychodynamic psychotherapeutic work with children with autism and it is organized according to the following aims: to summarize the state of research on the usefulness of psychoanalytic/psychodynamic psychotherapy when working with children with autism and to identify limitations within this body of research. Initially an introduction to psychoanalytic and psychodynamic theories is provided and the next step was selecting studies for inclusion in the review. This chapter is based on a search of published research available through September 2015. The SCOPUS, PsycINFO, CINAHL, Medline, ERIC and Cochrane databases were searched in 2013 and again in 2015 for the keywords: autism, ASD, psychotherapy, psychodynamic, psychoanalytic, intervention, treatment. The above search terms were combined with the universal 'Boolean operators'. Also, word endings were 'truncated' with the commonly used asterix standing for any or no characters at the end of a word.

A total of 812 abstracts were located during the database searches and of these, the ones not relevant to the review were excluded. Studies written in the

English language regarding the psychoanalytic/psychodynamic work with children with ASD from the year 1990 to 2015 were included. With respect to the dates included, the search was wider in this chapter, because there were not enough studies between 2000 and 2015. Also, due to the paucity of studies with higher level of evidence, Level IV and V were mostly included. In the next stage of selection process 17 studies were identified as meeting the inclusion criteria and were divided in two sections: 10 explored the usefulness of psychoanalytic psychotherapy with children with autism and 7 explored the effect of psychodynamic psychotherapy in children with autism. An overview of these papers is provided in sections 5.3-5.4. As it was also mentioned in chapter 4 the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement has been used as a reporting guideline for this literature review. The studies that are summarized in tables 14 and 15 are sorted based on the strength of the findings in relation to the types of study design. However, because of lack of a concurrent control group or experimental control in most of the studies, it is difficult to draw any firm conclusions regarding the effectiveness of psychoanalytic/psychodynamic psychotherapy with children with autism. Therefore, it is difficult to ascertain any observed effect is a "true" intervention effect, since the contribution of the natural course of the disorder or the effect of other concurrent treatments cannot be ruled out.

5.2 Psychoanalytic and psychodynamic theories

Psychoanalytic psychotherapy is based upon the theories and work of Freud and the focus of psychoanalytic psychotherapy is on psychological forces, impulse drives and wishes emerging from each individual that have their roots in infancy and early childhood. As commented by Kazdin (2000) one of the aims of psychoanalytic treatment is to offer insight for the resolution of inner conflicts. According to

Acquarone (2007), the psychodynamic approach is a combination of ideas derived from psychoanalysis with theories of infant emotional development, evolution, behaviours, cognition, psychology and neuropsychological research. As summarised by Kazdin (2000) psychodynamic psychotherapy focuses on psychological drives but it is not solely attached to psychoanalysis. Fonagy and Target (1996) suggest that the use of the relationship with the therapist is a vital medium that leads to therapeutic change, which is important when working with children with autism.

Psychodynamic psychotherapy derives from the clinical method of psychoanalysis and has been adjusted for use with children by Anna Freud, Melanie Klein, Erik Erikson and other psychoanalysts. Most child analysts agree on the important role of play in child psychotherapy and of the verbal interpretations of various emotional states of the child (Drucker, 2009). Drucker (2009) identified the psychodynamic model as a way of thinking about children, helping parents understand them and carefully choosing appropriate interventions.

One of the earliest psychoanalytic beliefs regarding the causes of autism had to do with the mother-child relationship and suggested that mothers were responsible for their child's autism because they were unable to form a warm relationship with their children (Bettelheim, 1967). Additionally, autism was described as a form of psychosis (Mahler, 1952). However, these conceptions are mostly considered out-dated and the genetic cause of autism is accepted by many psychotherapists nowadays (e.g. Shapiro, 2000). Whilst highlighting the organic cause of autism, Shapiro (2000) has suggested that the organization of these children's inner self should be considered during treatment. Moreover, the author stressed the importance of exploring the emotional deficits of this population as well. Other psychoanalysts view autism as a reaction to trauma. For example, Tustin (1993) suggests that it is the primitive

anxieties that dominate autistic disorders.

Psychodynamic/psychoanalytic treatment is meant to help with the social and emotional difficulties that children with autism face and it is used to promote the development of Theory of Mind through the modelling of empathy (Kernberg et al, 2012). Theory of mind has to do with the ability to understand that each person has their own mental state, thus they may think and feel differently (Astington and Edward, 2010). Baron-Cohen et al (1985) was one of the first to demonstrate that children with autism find it difficult to understand false-belief and other theory of mind tasks (Baron-Cohen, 2000). During psychodynamic psychotherapy the therapist contains the child's emotions and helps them regulate their own emotions in order to encourage self-regulation (Kernberg et al, 2012).

Roser (1996) suggested that psychoanalytic theory can be used as a tool to help us comprehend autism from a spherical angle. What sets psychodynamic/psychoanalytic treatment apart from other types of therapy with children with autism is that psychotherapists address issues, like Theory of mind, focus on deep emotions and that they do not focus on teaching skills (Greenspan, 2006). Instead, this type of approach highlights the importance of learning through relationships that include "emotionally-meaningful exchanges" (Greenspan, 2006, p.36) and promotes symbolic play and imagination (Barrows, 2002). Child psychotherapists help children with autism communicate their experiences and feel understood (Roser, 1996). It is believed that the therapeutic process is more effective when there is an active engagement with the child through play (Barish et al, 2004). Therefore, the relationship with the therapist leads to the facilitation of various treatment goals, such as a more positive relationship between the child and their parents (Barish t al, 2004).

As commented by Kernberg et al (2012), psychodynamic psychotherapy places emphasis on giving the opportunity to the child to lead during play and contributes to the development of the child's self-expression, as the therapist joins in the process. The therapist explores the child's developmental difficulties and internal conflicts through play and conversations and uses interpretations as a tool to help the child understand their own feelings and inner conflicts (Kernberg et al, 2012). The parents are also engaged in the therapeutic process and they learn to adapt to their child's changing needs (Kernberg et al, 2012), which makes the treatment more effective, and distinguishes the specific approach from other types of therapy.

The meaning of research and the use of appropriate methodologies for research in the field of psychoanalytic child psychotherapy have been debated over the years (Midgley, 2006). The most common form of research in child psychotherapy is single case studies written by the therapist according to their perspective of the treatment progress, which are considered to be in the bottom of the evidence base ladder. However, as Midgley (2006) suggests it is often difficult in the area of child psychotherapy to conduct a proper randomized controlled trial. Many psychodynamic interventions, for example, assess progress during therapy by measuring change in the individual's state of mind or inner world, which is difficult to measure using standardized tools. Therefore, often it becomes difficult in this field of research to check for internal validity and control for as many variables as possible in order to strengthen the validity of the results. Furthermore, in studies on child psychotherapy a so-called "clinically significant change" might not necessarily be statistically significant, so the change will be hard to recognize (Midgley, 2009). Most of the notions in psychoanalysis are attributed to processes that are difficult to measure, since they are often revealed over time and might be best explored via single

case studies. Especially in child psychotherapy for children with autism it is hard to measure change in the inner experiences of a child with autism during play (McLeod, 2011). However, the use of standardized measures is needed to assess this type of inner changes in order to provide the clinical and academic audience with more randomized controlled trials since they are still considered to be superior to observational methods as they are more rigorous and objective (Fonagy et al, 2002).

In the 1950s and 1960s psychoanalytic treatment for children with autism was the most common type of treatment in the western world but the trend has shifted nowadays to other types of treatment, e.g. behavioural therapy (Roser, 1996). The efficacy of psychoanalytic treatment of children with autism has been doubted throughout the years. The negativity towards the specific approach is mostly caused by misinterpretations regarding the context of psychoanalytic therapy with children (Alvarez, 1996). Theories about autism based on psychoanalysis are often rejected by psychiatric, cognitive and neuroscientific experts in the field (Merritt, 2012). Hobson (2011) suggests though that both psychoanalytic and non-psychoanalytic sides could gain an understanding from each other.

The majority of the studies reviewed here (see tables 14 and 15) were undertaken in clinically referred samples rather than samples specifically recruited for research (Tyminski & Moore, 2008; Vograft et al, 2007 and Fonagy & Target, 1996). The focus of eleven of the studies (see section 5.3) was the effect of psychoanalytic psychotherapy in children with autism. Six studies (see section 5.4) investigated the effect of psychodynamic psychotherapy in children with autism and one study focused on group psychotherapy (Tyminski & Moore, 2008).

5.3 Psychoanalytic Psychotherapy

Several studies in this field have reported small scale or single subject studies of psychoanalytic psychotherapy in autism with positive outcomes (table 14). All of these studies were undertaken in clinically referred samples.

Fonagy & Target (1996) conducted a retrospective study of case notes in order to assess the effectiveness of psychoanalytic psychotherapy. The authors hypothesized that children with pervasive developmental disorders, such as autism, would not be expected to respond in a lasting or generalizable way even to intensive therapy. Their study was based on 763 cases of psychotherapy completed at The Anna Freud Centre in London during forty years. The mean length of treatment was 14 months. These cases allowed useful analysis and data were extracted from these original clinical records. The cases included children from preschool to adolescence with emotional disorders; such as depression, disruptive disorders, such as conduct and attention disorders and developmental disorders, such as autism. However, the exact sample size of children that were diagnosed with autism is not mentioned. The measures that had been taken at the beginning and end of therapy included European (ICD-10) and North American (DSM-III-R) standard psychiatric classification systems. Individual symptoms were recorded following the Achenbach and Ederbrock's Child Behaviour Checklist and the Hampstead Child Adaptation Measure (HCAM) was used to assess the general adjustment of a child.

In comparing diagnostic groups the authors were interested to see whether it was more difficult to treat disruptive or aggressive children, and those with other form of severe and pervasive disorder, such as autism and if these children required more intensive treatment. Levels of improvement were measured based on the relief of symptoms and the transition of the child to a non-clinical classification. The authors

reported the effectiveness of psychoanalytic treatment for children with severe emotional disorders in the anxiety and depression spectrum. However, children with learning difficulties, pervasive developmental disorders (such as autism), attention deficit hyperactivity disorder and conduct disorder remained in the clinical range on HCAM measure. The authors stress that children with pervasive developmental disorders (e.g., autism) did not do well, even with prolonged, intensive treatment. The results of the study confirmed the initial hypothesis of the authors that is based on their theoretical suggestion that progress in this population is difficult due to the difficulties they face in their mental functioning, that cannot be changed through treatment. However, as it is speculated by the authors (Fonagy & Target, 1996) therapy could contribute to an easier adaptation and better quality of life for this population. Furthermore, the retrospective design could be stronger if the children were matched with others that were referred but not treated because in this study it is difficult to conclude that it was the psychoanalytic treatment alone that led to improvements in the children with severe emotional disorders in the anxiety and depression spectrum. Additionally, the fact that the assessment measures were taken only at the start and end of therapy along with the restriction to chart-based information limited any conclusive statements. Therefore, the length of the treatment other than the treatment itself might have caused the improvement of the children and since the study was based on archival records it cannot be definite that all important aspects of the cases were included.

Urwin (2002) presented four children with speech and language difficulties and autistic features. The study discussed varying psychoanalytic techniques and highlighted how they helped in the identification and substantial decrease of the children's autistic features. The author placed high importance on the trauma in the

parents' backgrounds and on how it made it more difficult for them to contain their children's anxieties. However, the author's views should be considered with caution, as it is suggested that separation and trauma might be a cause of autism.

In another study by Urwin (2011) an evaluation of child psychotherapy with seven children with Autistic Spectrum Disorder, is presented. The author discusses the theories that underpin the psychotherapeutic work with a child with autism and demonstrates the occasions when psychotherapy is required for a child with autism. The Hopes and Expectations for Treatment Approach (HETA) was used to evaluate the treatment of the seven children involved in the study. The Hopes and Expectations for Treatment Approach (HETA) form, was developed in an inner city London borough characterized by high levels of deprivation and ethnic diversity (Urwin, 2007). This measurement uses the initial clinical assessment in order to provide a baseline from which to create a set of therapeutic goals. It is a technique used to record and track the achievement of the therapeutic goals that are set for each patient specifically. The HETA form gives the opportunity to the parents and the therapist to record their views with respect to the expectations they have and to establish if the therapeutic goals have been reached (McLeod, 2011). The HETA form is then revisited in the end of the second term of treatment and again at the end of the year. The author reports that, based on the HETA, the children benefited from psychotherapy and the reports sent from the children's schools confirmed their progress. Only one child out of the seven was the exception as, during treatment, he became more emotionally disorganized. A full description of three of the cases is also provided in this study.

However, the results in both studies (Urwin, 2002; 2011) seem to express the treating clinician's personal opinion, which could challenge the validity of the

outcome and makes it difficult to generalize the findings. The findings are limited by investigator biases, the lack of experimental control and poor validity for the measure used. The collection and analysis of data might be biased by the subjectivity of the author and cannot be generalized. Also, uncontrolled studies, especially those with very small sample sizes, of a population whose symptoms are so diverse, make it difficult to yield data with respect to the effectiveness of the treatment.

Similarly to the Urwin (2002) study the impact of trauma on children's development, with particular reference to the acquisition of language, is revisited in the Mori (2001) and Barrows (2002,2004) case studies. Mori (2001) presented a case of one boy with autism who had psychoanalytic psychotherapy. As it is also seen in the Urwin (2002) paper the therapeutic process in the Mori (2001) paper is described in detail and the conclusions of the study seem to express the treating clinician's view. According to the results the therapist was able to engage the child after one year of therapy, allowing him eventually to come out of withdrawal and communication became possible. Through the description of Barrows (2002) single case, the importance of taking an active role during therapy in order to help a child emerge from their withdrawn state was stressed. According to Barrows (2002) the psychotherapeutic approach that was followed proved to be helpful in facilitating the development of the child's language and imaginative play. Barrows (2004) modified the version of his original paper also and used the same clinical material to show that psychoanalytic psychotherapy can be a helpful form of treatment for a specific sub-group of children with autism; those who had experienced trauma early in their lives. Barrows (2004) reviewed the literature with respect to this specific sub-group of children with autism and presented the theoretical framework that his work was based on. The boy benefited from the treatment but no measurements were used to confirm

these observations. As commented previously the conclusions drawn from this study are based on the author's clinical view. Also, it seems that the study is embedded in a strong environmental causality model for autism, which suggests that early trauma might cause autism.

A number of studies (as seen in table 14) used a clinical vignette to illustrate that psychoanalytic psychotherapy can help children with autism. In the Kalish-Weiss (2008) study the Behaviour Rating Instrument for Autistic & Atypical Children (BRIAAC; Ruttenberg et al, 1974) was used to evaluate the child's behaviours. The BRIAAC is a standardized procedure that measures specific observed behaviours of a child during a two-year period while the child is in the presence of a familiar adult (Ruttenberg et al, 1974). The BRIAAC is based on psychoanalytic theory and developmental milestones. However, no statistical analyses were reported of the differences on pre and post treatment measures. Also, no later BRIAAC assessment was provided for data comparison. Although the study reports positive outcomes associated with the certain model, the weaknesses in the design and data reporting limited the generalizability of the results.

In the Fisher (2000) case study clinical material from the author's work with a child with autism was used. Fisher (2000) also based the study on one clinical vignette about a boy with autism. The author described the therapeutic process with that child whilst explaining the theoretical underpinnings of the psychoanalytic work. The progress of the child was illustrated as the treatment continued and the author mentioned that after four years of therapy the boy was fully verbal, well coordinated and his cognitive skills were developed to his age level.

In a similar vein, Alvarez & Lee (2004) carried out a single case study of a four-year-old child with autism and explored the changes that occurred during the

three years that the child received psychoanalytic psychotherapy. The Childhood Autism Rating Scale (CARS, Schopler et al, 1989) and the Autism Diagnostic Interview (ADI-R, Lord et al, 1986) were used to assess the child prior treatment. The assessment showed that the child had several impairments in the areas of reciprocal social interaction and communication along with repetitive, stereotyped behaviours. The child was in therapy three times a week over 42 months and the sessions were videotaped, in order to be rated twice every year. In addition, Alvarez & Lee (2004) carefully tracked the number of times that the patient looked at the therapist in order to analyse the process of change. Based on the authors' clinical observations the psychoanalytic approach contributed to the improvements in all of the child's areas of deficit. The child was not reassessed though on the CARS and ADI-R. Similarly, the psychoanalytic treatment of a six year old with Asperger's Syndrome was the focus of the Gould (2011) case study. The therapy consisted of once per week sessions for two and a half years and based on the author's notes the child progressed in a positive manner during the treatment process and gradually felt more powerful and safe.

Shaft (2011) reported a clinical vignette of a four-year-old girl with Asperger's Syndrome that he treated psychoanalytically. The author suggested that all the psychoanalytic tools he used were vital to the positive progress of the child over time and led to the decrease of the girl's intense anxieties. Shaft (2011) described the course of the three years of treatment and how the child progressed in her emotional development. However, in all of the studies (Kalish-Weiss, 2008; Barrows, 2002 and Fisher, 2000; Alvarez & Lee, 2004; Gould, 2011 and Shaft, 2011) the validity of the results is weakened by the use of only one child, the lack of standardized measures and by the fact that the findings were based on the treating clinicians' views and were purely descriptive.

Table 14. Psychoanalytic Psychotherapy

Study	Country	Sample	Type of treatment	Outcome Measures	Key findings
Fonagy & Target (1996) Retrospective study Level IV evidence	UK	763 cases of psychotherapy	Psychoanalytic and Psychodynamic psychotherapy	Achenbach and Ederdock's Child Behaviour Checklist, HCAM	- 28% of children with pervasive developmental disorders (e.g. autism) improved significantly - Children with pervasive developmental disorders did not do well and remained in the clinical range on HCAM measure - Treatment at a younger age was associated with better results
Alvarez & Lee (2004) Case study Level V evidence	UK	4-year-old child with autism	Psychoanalytic psychotherapy	Video rating of recorded sessions	- Improvements in all of the child's areas of deficit -
Barrows (2002,2004) Case study Level V evidence	UK	3-year old boy with autistic features	Psychoanalytic psychotherapy	Clinical observations	- Child became less withdrawn - Improvement in language and imaginative play -
Fisher (2000) Case study Level V evidence	USA	6-year old boy with autism	Psychoanalytic psychotherapy	Clinical observations	- After 4 y of therapy the boy was fully verbal, well coordinated and his cognitive skills were developed to age level -
Gould (2011) Case study Level IV evidence	USA	6-year-old child with autism	Psychoanalytic psychotherapy	Clinical observations	- Positive progress throughout treatment - Increased feelings of security and power
Kalish-Weiss (2008) Case study Level V evidence	USA	2,5-year old boy with autism	Psychoanalytic psychotherapy	BRIAAC	- Improvements in language - Increased ability to express inner feelings
Mori (2001) Case study Level V evidence	Japan	One boy with autism aged 4 y Treatment lasted for 7	Psychoanalytic psychotherapy	Clinical observations	- After a year the therapist was able to engage the child as he came out of withdrawal

		y			- Communication was promoted
Shaft (2011) Case study Level V evidence	USA	4-year-old girl with Asperger's Syndrome	Psychoanalytic psychotherapy	Clinical observations	- Positive progress over time - Decrease of the girl's intense anxieties
Urwin (2002) Case study Level V evidence	UK	4 children with autistic features and language delays aged 3-4 y	Psychoanalytic techniques	HETA	- Parents became more emotionally available to their children - The treatment encouraged language development and the autistic features decreased -
Urwin (2011) Case study Level V evidence	UK	7 children with ASD aged 4-12y	Psychoanalytic psychotherapy	Clinical observations	- Positive changes in the children (from a psychoanalytic point of view) after one year except for one who did not progress - Improvement in the quality of life for the child and family -

5.4 Psychodynamic Psychotherapy

Six studies (table 15) explored the effect of psychodynamic psychotherapy in children with autism and one study investigated group psychotherapy (Tyminski & Moore, 2008).

In the Kobayashi (2000) study two cases of children with autistic features in early infancy who had psychodynamic psychotherapy with their mothers were discussed. The main goal of the author was to promote affective communication between mother and child. Mother–infant psychodynamic psychotherapy was conducted in both cases, which brought to light the internal world of the mothers in the course of therapy. Also, this therapy clarified one aspect of the factors impeding affective communication between mother and child. Two Japanese developmental tests were implemented to monitor the children's development: The Tsumori-Inage Development Test (Tsumori and Inage, 1987) and the revised Kyoto Scale of Psychological Development (Ikuzawa et al, 1985). The results showed that although delay in overall development remained unchanged, improvement was achieved in the areas of language and sociability. Also, attachment behaviour was significantly improved in the children but affective communication with their mothers did not improve easily. Larger studies on the effect of psychodynamic psychotherapy are needed to allow statistical comparisons and to provide stronger scientific support for being beneficial.

Two case studies presented by Bromfield (2000) and Olesker (1999) suggest that psychodynamic psychotherapy might be beneficial for children with autism and both authors identify the understanding of the emotional difficulties of a child with autism as the key to the treatment. Attempting to address the benefits of psychodynamic psychotherapy Bromfield (2000) and Olesker (1999) used material

from their own clinical work and described the process of treatment with a child with autism. However, no measurements were used that might confirm these gains other than their own clinical point of view. Similar conclusions are drawn from Ruberman (2002), who reviewed the Bromfield (2000) and Olesker (1999) studies. The author stresses the importance of psychodynamic psychotherapy and that children with autism should be offered such types of treatment. Also, based on the author's personal opinion, it is argued that psychotherapeutic interventions for children with autism should begin as early as possible in order to have better results.

Hoffman and Rice (2012) reported on a case of psychodynamic treatment with a child with autism from age 3.5 years old through later adolescence. The specific approach aimed to promote the development of a reliable relationship with another person, the ability to release and verbalize his feelings via play or other activities and to gain understanding of the causes of his own behaviours and of the use of various coping mechanisms. Throughout the years the sessions occurred two to three times per week and the therapist contacted the parents regularly. The authors video-recorded an interview with the child when he was 19 years old in order to explore his own understanding of the therapeutic process and the accomplishments that were or were not made. The Wechsler Adult Intelligence Scale (WAIS-3rd ed; Wechsler,1955) was used to assess the participant's progress and the results showed an above average score, which might have been attributed to his involvement in psychodynamic psychotherapy. Nonetheless, similarly to the previous case reports, the Hoffman and Rice (2012) study is unable to account for the child's improvement by psychodynamic psychotherapy solely.

Sherkow (2011) explored the use of psychodynamic play in order to promote the formation of connections that can tolerate conflict and defence, to establish basic

trust, foster emotional and cognitive connections and help children with autism identify with their parents. The author described her clinical work with a 2.5-year-old boy on the autism spectrum who was in treatment until he was 6 years old. Based on the author's clinical opinion the boy benefitted from the treatment, since there was an improvement in the areas of self-regulation, play and imagination along with a decrease in aggressive behaviours. Sherkow (2011) suggests that psychodynamic intervention influences the brain's neuroanatomy by creating connections between the "thinking brain" and the "feeling brain" during therapeutic play with a child. In addition, Sherkow (2011) identified the importance of the mother's active participation in therapy and how the mother-child relationship is affected by a diagnosis of autism. According to the author, the mother in the case report found it difficult to deal with the reality that her son had an impairment and the boy viewed his mom as frightened. Alvarez & Reid (1999) also highlighted the importance of not only the mother's involvement but the father's and siblings' as well. Alvarez & Reid (1999) outlined their psychotherapeutic techniques in treating children with autism and demonstrated the significance of the parents' and siblings' participation and support in order to help the child progress further.

Vorgraft et al (2007) conducted a preliminary study aiming to evaluate the Mifne treatment model[10] (Alonim et al., 2002), a novel intensive therapy program, in young children with autism. The study sample consisted of twenty-three children with pervasive developmental disorder treated at the Mifne Institute in Israel between 1997 and 1999. Fourteen of the children met the criteria for autistic disorder and nine for pervasive developmental disorder not otherwise specified (PDD-NOS). Two children

[10] The Mifne treatment model (Alonim et al., 2002) is a sequential family program for children under the age of 5 who have been referred with a diagnosis of PDD/ASD (autistic spectrum disorder).
The approach is based on Bowlby's (1969) attachment theory and incorporates psychodynamic concepts introduced by Tustin (1981) and the systemic approach to family therapy of Minuchin (1974).

were also diagnosed with comorbid intellectual impairment and one with specific developmental language disorder. The authors used home videos of the children from before treatment, along with videos recorded at the institute after the 3-week intensive treatment and before and after another 6 months of continued treatment at the families' homes. The videos were coded and blind rated using the Childhood Autism Rating Scale (CARS; Schopler et al, 1988) and the Social Behaviour Rating Scale (SBRS; Feinstein and Walters, 1982). The results showed significant improvement on both scales after 3 weeks and after 6 months. However, the difference from baseline was statistically significant for only two items on the CARS (emotional response and fearful and nervous response) and specific items on the SBRS (awareness of others' emotional states, mutuality, and overall impression on the home video assessment; awareness of others' emotional states, joint positive emotional experiences, emotional availability, reactions to social initiative, and overall impression on the Mifne video assessment). In addition improvement was noted in total scores for both scales with an exception of the CARS home videos. It is also interesting to note that although all children showed some improvement, only in the ones that were more severely affected by autism did this improvement reach statistical significance. Nonetheless, the children with the most severe symptoms had more room for improvement than the ones that were characterized by low baseline values.

Furthermore, the fact that the diagnoses were not made on the basis of structured diagnostic instruments, but rather made by clinicians and then verified by chart review, can be considered as a limitation. The use of a randomized controlled trial with standard interventions as control treatments might have strengthened the results.

Tyminski & Moore (2008) explored the impact of group psychotherapy[11] on children with PDDs (pervasive developmental disorders). The participants were thirty-nine children, 38% of the participants were diagnosed with autism, 8% with Asperger's Syndrome and 54% with a PDD not otherwise specified. These children participated in five psychotherapy groups. Two of the groups contained six children and the rest contained five children. Two months after the beginning of therapy a baseline assessment of social development was obtained and follow-up assessments of all study measures were obtained 14 months, on average, after the start of therapy, with a range of four months to three years.

Tyminski & Moore (2008) aimed to assess the children's cognitive functioning and social development at home and at school before and after treatment. The detailed reporting of the measures used and the statistical analysis strengthens the validity of the results. In order to assess the children's cognitive functioning the 'Sally-Ann' test, the 'Smarties' test and the Ravens Progressive Matrices (RPM; Raven & Court, 1976,1991) were used. In addition, the Vineland Adaptive Behavior Scale (VABS; Sparrow, Balla & Cicchetti, 1984) was used to measure children's socialization communication, and daily living skills at home and the Tyminski Social Skills Checklist (SSC) was used to obtain the teacher's assessments of children's social behaviour quickly and easily within the educational environment. According to the results children's social development at home and at school showed significant gains after the group psychotherapy intervention. Also, it was found that the children with a coherent theory of mind[12] had higher VABS scores at both baseline and at

[11] Group psychotherapy helps children with pervasive developmental disorders (PDDs) in the areas of social interaction, emotions and helps them feel that they belong in a community (Tyminski, 2005).

[12] Researchers usually use the term "theory of mind" when they refer to the children's understanding of other people as mental beings with desires, beliefs, feelings and intentions (Astington & Baird, 2005).

follow –up. Overall, this study reports positive outcomes associated with group psychotherapy but the lack of control group weakens the results, since the maturation of the children might have caused the improvement seen in the participants.

Table 15. Psychodynamic Psychotherapy

Study	Country	Sample	Type of treatment	Outcome Measures	Key findings
Tyminski & Moore (2008) Pre-post Level III evidence	USA	39 children, 38% with autism, 8% with Asperger's and 54% with a PDD not otherwise specified in 5 psychotherapy groups	Group psychotherapy	Sally-Ann test, Smarties test, Ravens, VABS, SSC	- Children's social development at home and at school showed significant gains
Vorgraft et al (2007) Retrospective study Level III evidence	Israel	23 children with pervasive developmental disorder treated between 1997 and 1999	3-week intensive method of treatment based on a psychodynamic approach	Video rating, CARS, SBRS	- Significant improvement in CARS and SBRS - Difference from baseline was statistically significant for only two items on the scales
Bromfield (2000) Case study Level V evidence	USA	7-year old boy with autism	Psychodynamic play therapy	Clinical observations	- Slow and steady improvement in several areas of deficit - Improved interaction with peers and family
Hoffman & Rice (2012) Case study Level V evidence	USA	3.5-year old boy with autism	Psychoanalytically informed psychodynamic therapy	WAIS-3rd ed	- Above average score in the Wechsler Adult Intelligence Scale (WAIS; 3rd ed.) - Developmental gains in the areas of communication and social skills -
Kobayashi (2000) Case study Level V evidence	Japan	a) Boy with autism aged 1 y 8 mo b) Boy with autism aged 3 y 2 mo	Mother–infant psychodynamic psychotherapy	Tsumori image development test, Kyoto scale of psychological development	- Delay in overall development remained unchanged - Improvements in the areas of language and sociability and attachment behaviour - No significant improvement in affective communication with their mothers
Olesker (1999) Case study Level V evidence	USA	4-year old boy with autistic features	Psychodynamic psychotherapy	Clinical observations	- Gains in self-regulation - Decrease of extreme and primitive defensiveness, e.g. obsessive-compulsive behaviour and withdrawal

Sherkow (2011) Case study Level V evidence	USA	2,5-year old boy on the autism spectrum	Psychoanalytically informed dyadic psychodynamic approach	Clinical observations	- Decrease in autism symptoms - Development of cognitive and affective connections

5.5 Summary

The studies reviewed here focus on the usefulness of psychodynamic/psychoanalytic treatment with children with autism and reflect the ambition of child psychotherapy researchers to carry out studies in order to add to the evidence base for this type of approach. The majority of studies were rated level V, indicating that overall the body of evidence supporting outcomes for children with autism using psychotherapy tend to be descriptive rather than experimental. Based on McLeod (2011) there are four factors that make case studies "critical in building a solid and relevant knowledge base for therapy: 1) a narrative way of knowing, 2) complexity, 3) context and 4) practical expertise in action " (McLeod, 2011, p. 252).

In regards to complexity it is possible though to collect many observations from each participant in large-scale studies as well but when conducting a case study it is easier to describe and examine evidence of more complicated processes. Nonetheless, in some case studies the level of complexity can cause chaos and lose its meaning (McLeod, 2011). Also, with respect to "practical expertise in action", in larger scale studies the practitioners may also be involved and their professional knowledge may be applied, as it is seen in several case studies.

In the majority of case studies in this field of research, what the authors present may be their personal perception of what happened during therapy and it becomes difficult for the readers to draw their own conclusions. Larger studies can increase the ability to generalize to a wider population, which is not feasible when carrying out a case study. Often overlooked in the studies investigating the use of psychodynamic/psychoanalytic psychotherapy with children with autism is the control of relevant variables that might have influenced the outcomes. Thus, in the majority of the studies it is difficult to demonstrate that it was psychotherapy alone

that produced change. Also, in studies where there was no change reported in the participants it cannot be concluded without a suitable control that psychotherapy had no effect, since it may have helped the participants not to get worse.

The conclusions from the studies that focused on the use of the psychoanalytic and psychodynamic approach discussed in this chapter and presented in tables 14 and 15 showed how this type of approach can facilitate positive changes in the development of children with autism, mainly based on the treating clinicians' views.

Sometimes psychotherapy is considered in itself to be a subjective process and many of the variables that psychotherapists are asked to rate can be subjective as well, e.g. empathy, transference. The more subjective a rated variable is, the lower the inter-rater reliability and that leads to a high risk of bias in such studies (Heppner et al, 1999). As it can be seen in most of the studies discussed here psychotherapists often complete self-report measures, which could be considered as a matter of convenience. On the other hand there is an argument for giving the chance to the readers to become part of the psychotherapy process as they share the psychotherapist's personal views and they identify his/her perspective in research (Markin & Kivlighan, 2007). Kaplan-Solms and Solms (2000) suggest that a theory can be built on the basis of the understanding that derives from a large number of cases. There are a number of limitations though across all of these studies, which weakened the validity of the findings.

The applicability of psychodynamic/psychoanalytic theory in the treatment of children with autism should be explored further by comparing it with other modes of treatment. Case presentations though might contribute to the emergence of new ideas. It is argued by some researchers (e.g. Stake, 1995) that case studies help bridge the gap between research and clinical practice. Case studies allow the researcher to

examine the process of treatment in far more detail than might be possible if a larger number of participants was included and provide a more in-depth analysis of the context of the case which cannot be reflected in lager-scale study.

As reported in the Criteria for Evaluating Treatment Guidelines (APA, 2002), in regards to the evaluation of treatments there are two dimensions taken into consideration; treatment efficacy and clinical utility. Treatment efficacy is described as "a valid ascertainment of the effects of a given intervention as compared with an alternative intervention or with no treatment in a controlled clinical context" and clinical utility is defined as "the applicability, feasibility and usefulness of the intervention in the local or specific setting where it is to be offered" (APA, 2002, p.1053). Based on the APA (2002) the strongest studies regarding validity are considered to be the Randomized Controlled Trials and the type of research that is in the bottom of the hierarchy of evidence are studies based on clinical opinions and observations. Rigorous controlled trials are sparse in the field of psychodynamic/psychoanalytic psychotherapy, reflecting the difficulties in the randomization of participants and in assigning a control group. Therefore, the fact that most of the studies reviewed here are clinical vignettes based on the authors' clinical opinions, limits the ability to draw definitive conclusions about the efficacy of psychoanalytic/psychodynamic treatment with children with autism. Additionally the use of a very small sample and the reliance on clinical notes and not on standardized assessment measures in most of the studies are considered major limitations.

The studies reviewed here though could be considered as a start in attempting to study the effect of psychotherapy on children with autism and they could be used conceptually in order to guide further thinking around future research in this area. As it can be seen from the review the formation of an evidence base for psychoanalytic

and psychodynamic psychotherapy is still at an early stage, but the conclusions drawn from the studies demonstrate that there is preliminary evidence for the positive effect of this type of approach on children with autism, although one must bear in mind the methodological limitations to the studies reported here.

Chapter 6 Occupational Therapy

6.1 Introduction

Occupational therapy (OT) is considered as one of the most common types of therapy for children with autism after speech and language therapy (Watling et al, 1999; McLennan et al, 2008). The primary purpose of the present chapter is to review the relevant research literature on the usefulness of occupational therapy with children with autism and to present an overview of the findings.

The areas that occupational therapists mostly focus on are: sensory processing, attention, play, coordination, and fine motor skills. According to Hodgetts and Hodgetts (2007) sensory interventions are the most commonly used procedures by occupational therapists with children with autism. However, within occupational therapy complementary and alternative treatment can be implemented as well, for example treatments that are not considered to be traditional, like hippotherapy (Irvin et al, 2014). Dunn (1999) suggested that when individuals with autism find it difficult to become accustomed to everyday sensory input then they become agitated and inattentive. Difficulties in sensory processing may result in hyperactivity, restlessness and stereotypic behaviours. Occupational therapists attempt to decrease these behaviours by using various sensory-based treatment techniques (Ayres, 1979).

Bagatell & Mason (2015) carried out a scoping review of the occupational therapy literature that was related to autism spectrum disorders from 1980 to 2013. They report that from 2000 there was a significant increase in the number of publications exploring the impact of occupational therapy on autism. The authors also noted that initially most of the occupational therapy studies utilized a single-subject design, which is not considered strong in the evidence-base hierarchy. However, over

the last years there has been a shift to more randomized controlled trials that include fidelity measures (e.g. Pfeiffer et al, 2011).

According to Clark et al (2004) occupational therapists aim to collaborate with parents of children with autism and other professionals in order to help children decrease maladaptive or other negative behaviours. The area of communication is considered to be challenging for many children with autism and communication skills are required to satisfy everyday occupational needs, hence daily routines like play, learning and socialization (Clark et al, 2004). Hebert et al (2014) investigated the role of occupational therapy for the promotion of communication in children with autism. The participants were 21 clinical occupational therapists and speech and language pathologists who were included in semi-structured audio-recorded focus groups, using a qualitative design. Based on the findings there was a general agreement about the importance of occupational therapy in promoting early communication skills.

In the current chapter available research was reviewed in an attempt to locate empirical research that explored the usefulness of occupational therapy with children with autism. The search of the literature was conducted using the SCOPUS, PsycINFO, CINAHL, Medline, ERIC and Cochrane databases. The body of research was narrowed down during the search by keywords such as autism, ASD, occupational, therapy, sensory, integration. The above search terms were combined with the universal 'Boolean operators'. Also, word endings were 'truncated' with the commonly used asterix standing for any or no characters at the end of a word. The literature was initially searched for studies published between 2000-2015 in order to offer the most up to date evidence, but due to the paucity of relevant studies a wider search was initiated including dates between 1990-2015.

Abstracts of the resulting studies (n=1044) were then evaluated for the

following criteria: inclusion of a population of children diagnosed with autism spectrum disorders (ASD), provision of occupational therapy, availability of the papers in English and publication of studies between years 1990-2015. Different occupational therapy techniques have been developed, studied and applied in an effort to help children with autism. The reviewed papers here comprise a number of different approaches and examine various types of occupational therapy. Thirty studies met the inclusion criteria for this review and chapter 6 is divided in four sections. The following section includes an overview of 16 studies related to sensory integration therapy with children with autism and the other sections focus on the use of weighted vests (n=9); aquatic therapy (n=3) and OT incorporating animals (n=2). Finally a summary is provided with respect to the findings of the research. As it was also mentioned in chapters 4 and 5 the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement has been used as a reporting guideline for this literature review and the order of the studies in table 16, 17 and 18 reflects the strength of the findings in relation to the types of study design.

6.2 Sensory Integration Interventions

The participation in activities of daily living can be a challenge for children with autism and the fact that they do not process sensory information easily makes it even more challenging for them. Occupational therapy with a sensory integration approach (OT/SI) is used to help children achieve more in their daily life (Schaaf & Miller, 2005). Occupational therapist, Jean Ayres (1972), was the first to develop the theory of sensory integration. Sensory integration refers to "the process by which the brain organizes and interprets external stimuli such as touch, movement, body awareness, sight, sound, and gravity. It has been postulated that "certain behavioural

and emotional problems result from the malfunctioning of this process" (Sensory Integration Therapy: Medical Policy, 2012, p. 2). Occupational therapists usually apply sensory interventions to children with autism in order to help them with their sensory difficulties (Kadar et al, 2012) but also to help ameliorate behavioural problems and repetitive or stereotypical behaviour. The aim of sensory integration therapy is to help children, who have significant difficulty processing sensory information and offer them the skills to become gradually more and more independent. According to Greenspan and Wieder (1997), 20% of children with autism spectrum disorder are hypersensitive to sensation, 39% are under reactive to sensation, and 36% demonstrate hypersensitivity along with hyposensitivity.

Children with autism often exhibit restricted and repetitive behaviours also known as stereotypical behaviours (American Psychiatric Association, 2000). Sensory integration therapy has often been used to decrease stereotypic behaviours of children with autism (Sniezyk & Zane, 2015). If stereotypies are persistent they can hinder everyday life activities like learning or socializing and could stigmatize the child (Goldman & Greene, 2013). Based on a sensory perspective children with ASD present with stereotypical behaviours in order to balance visual, vestibular, auditory and tactile stimulation (Gabriels et al, 2008).

Sixteen studies have investigated interventions based on Sensory Integration therapy (SIT) since 2000 (table 16). Consistent with previous reviews of sensory integration therapy (Dawson & Watling, 2000 and Smith et al, 2005) Lang et al (2012) carried out an international systematic review of 25 studies on the use of sensory interventions for children with autistic spectrum disorders and they concluded that there is not enough scientific evidence to support the use of sensory integration therapy for children with autism.

More specifically, the results from 3 of the 25 reviewed studies suggested that sensory integration therapy was effective. On the contrary, 8 studies reported mixed results and 14 found no benefit. The three that suggested positive effects of SIT were classified at the lowest level of certainty because of methodological restrictions. Six studies out of the fourteen that reported negative results were classified at the conclusive level and five out of the eight with mixed results, were classified as mixed because some participants benefited from SIT and others did not.

In two studies (the Pfeiffer et al, 2011 and Bagatell et al, 2010) the Sensory Processing Measure[13] (SPM: Parham et al, 2007) was used to identify and describe sensory processing issues. Bagatell et al (2010) used a single-subject design to examine the effectiveness of therapy ball chairs on classroom participation, more specifically on in-seat behaviour and engagement in six children with autism. Participants sat on therapy ball chairs during class circle time and after five days; participants were given the choice of sitting in therapy ball chairs or regular chairs. The results of the study were mixed since the ball chairs did not appear to be effective for all children. Additionally, a stronger design e.g. an alternating-treatment or multiple-baseline design would strengthen the results. Marr et al, (2007) also conducted a form of sensory integrative therapy treatment in a classroom during circle time. The study explored the effect of Sensory Stories on decreasing disruptive behaviours during circle time in three children with autism and on decreasing stereotypical behaviours in one child with autism. The intervention lasted for twelve days but due to child absences each child's targeted behaviour was observed for eight to nine sessions. The results showed that all children benefited from Sensory Stories

[13] The SPM asks primary caregivers to complete 75 items (classroom form is 62-items completed by teachers) and generates eight standard scores that describe: social participation, vision, hearing, touch, body awareness, balance and motion, planning, and total sensory system. Ultimately, children's sensory processing is classified as "typical", "some problems" or "definite problems" (Parham et al, 2007).

but one child was already improving during baseline, which did not allow definitive conclusions to be made. The generalizability of the findings in both studies (Bagatell et al, 2010 and Marr et al, 2007) is limited by the use of convenience sampling and the short length of the studies.

In the Pfeiffer et al (2011) study and in the Van Rie and Heflin (2009) study issues related to learning were also measured. In the Pfeiffer et al (2011) study thirty-seven children were randomly assigned to a fine motor or sensory integration treatment group. Social responsiveness, sensory processing, functional motor skills and social-emotional factors were assessed using standardized tools pre and post interventions. The results of the study were mixed as positive gains were identified in both groups. The sensory integration group though displayed significantly fewer autistic mannerisms than the fine motor group, which is consistent with the Watling and Dietz (2007) findings. Other studies have aimed to determine if there is a relationship between sensory dysfunction and learning (Van Rie & Heflin, 2009). Four children with autism who exhibited sensory-based behaviours (e.g. jumping up from the floor/chairs, walking on tiptoes or engaging in verbal stereotypy) participated in the study. The sensory activities implemented to the children included slow linear swinging and fast bouncing on an exercise ball and the authors applied a control condition of the children listening to a story, with sensory activities, during 5-min sessions. Van Rie and Heflin (2009) measured the times that the children responded correctly on selected tasks (receptive or expressive identification of community helper and safety signs flash-cards) during instructional sessions, and they reached mixed results. Based on the findings a functional relation between completing a sensory activity and positive changes in learning was identified for two of the four participants and for the other two there was no clear functional relation found.

However, sensory difficulties might be partly the cause of disruptive behaviour and learning difficulties, but intervention addressing this might still not be helpful for all children. That is, a relationship between sensory and learning problems is not the same as a relationship between sensory intervention completion and improvement. The results are strengthened by the random assignment of participants and rigorous methodology but the generalizability is limited by the small sample size and mixed findings.

A similar study design was used by Fazlioglu & Baran (2008) who also investigated the effect of a sensory therapy integration program but examined direct effects on the sensory problems of children with autism. The participants were divided into 2 groups (control and treatment), each comprising 15 children. The control group children did not participate in the sensory integration program, but attended regularly scheduled special education classes. The intervention program used in this study was based on "The Sensory Diet" and included a prescribed schedule of somatosensory stimulation activities targeting 13 behaviours across sensory modalities and motor skills development. The participants were assessed before and after the program on a checklist, the Sensory Evaluation Form for Children with Autism, developed to evaluate sensory characteristics of children with autism. The results indicated that the sensory integration therapy program positively affected the group of children that followed the sensory integration therapy program and symptoms decreased. However, the results of the study are limited, due to the lack of a fidelity measure and the fact that it was not clarified whether it was conducted in a blinded manner. In addition, it was a short-term study (12 weeks) and this might have affected the findings because the children were not followed up to determine if the benefits of the treatment were maintained.

The use of a sensory diet was also included in a study by Sniezyk & Zane (2015). Sniezyk & Zane (2015) utilized a within-subjects-reversal design to investigate the effect of various sensory activities (vestibular movements via the swing, deep pressure, sensory diet) on the stereotypy of three children with autism. Stereotypy was defined as a "rhythmic, repetitive, exaggerated or unusual tightening of the muscles of either a particular body part or entire body in the absence of an appropriate environmental context" (Sniezyk & Zane, 2015, p. 15). The authors reported that there was no clear functional relationship between positive changes in dependent measures and the application of a sensory intervention. Potential limitations of the study include the fact that there was no control group; that for one of the children all features of the reversal design were not applied and the lack of blinded data which is acknowledged by the researchers. Nevertheless, this study is strengthened by the rigorous inter-observer agreement and the measurement of the fidelity of the procedures in order to ensure that the implementation of the procedures was accurate.

A more rigorous study by Schaaf et al (2013) assessed the use of a manualized sensory intervention (applied 3 times per week during hour-long sessions for 10 weeks) in 17 children with autism, aged 4-8 years old and compared them to a control group (n=15) who received the usual care (e.g. SLT, behavioural therapy, educational programs) . The authors used standardized assessments to assess children's cognitive and sensory skills along with the Goal Attainment Scaling (GAS) to measure the progress of each child's personalized goals. The fidelity of implementation of the procedures was also verified in this study. The results of this study correspond with previous findings about the efficacy of a sensory intervention (Fazlioglu & Baran, 2008). That is, higher scores on the outcome variables were reported after the

implementation of the treatment, which supports the use of a sensory intervention for children with autism. However, the authors mention that their results are limited by the use of measures that are not validated for use as outcome measures in shorter intervention periods and by not measuring directly the behaviours of the children that might have been affected by the sensory intervention. Very few studies have been conducted outside of Europe and the US. One exception is that by Iwanaga et al (2014) who carried out a study exploring sensory integration therapy compared to social group therapy in 20 children, aged 2-6 years old, with high functioning autism in Japan. The study lasted over an 8 to 12 month period. The sensory integration therapy group participated in swing, balance beam, trampoline and ladder activities and the children in the group therapy had social skills and communication training, kinetic activities and play activities with their parents. The results of the study showed that sensory integration therapy helped improve children's motor coordination and nonverbal cognition. Nonetheless, both groups showed improvements in their verbal skills. The Japanese version of the Miller Assessment for Pre-schoolers was used to assess the children. The findings of the Iwanaga et al (2014) study support the effectiveness of sensory integration therapy but the fact that only children with high functioning autism were included is of interest. It may be that children with high capacity can better access this type of therapy. In addition, the number of children in each group was different, because the Iwanaga et al (2014) study included a retrospective analysis of previously collected data, both types of therapy were different in their therapy members and the fact that the first author did both testing and the sensory integration treatment might have biased the results.

Five single subject studies (Case-Smith & Bryan, 1999; Linderman & Stewart, 1999; Watling & Dietz, 2007 and Gee et al, 2014) examined the effect of sensory

integration with children with autism. Case-Smith & Bryan (1999) recruited five boys with autism and when the study started each participant had been without any kind of therapy for a month, since the children had been on a break for the winter. A 3-week baseline phase was initiated during which the children attended the school but did not have occupational therapy. In the fourth week Sensory Integration treatment and consultation with teachers was implemented and lasted 10 weeks. Case-Smith & Bryan (1999) identified gains in mastery play and adult interaction along with decreases in non-engaged behaviours. Watling & Dietz (2007) explored the immediate effects of sensory integration intervention on the behaviour and task engagement of four children with autism. The sensory integration treatment was compared to a play scenario for reducing undesirable behaviours and increasing engagement in purposeful activities. The results showed that when effects were measured immediately after intervention, short-term sensory integration had similar effect on undesired behaviour and engagement of the participants to the play scenario. Furthermore, the data gathered from the research personnel and parents suggested that sensory integration had a positive effect on transitions, socialization, compliance and general behaviour regulation during the sessions and in the home environment. However, there is potential for bias in subjective observations recorded by personnel and parents. Linderman & Stewart (1999) recruited two children from the occupational therapy department at a Health Centre in Washington who had participated in a multidisciplinary evaluation by the Health Centre's Neurodevelopmental Group. The participants that were excluded from the study were those who were not pre-school-age; were having or had sensory integrative based occupational therapy and those who were unable to tolerate the therapeutic techniques or the repeated measurement design during the initial evaluation, which might have

biased the results. Linderman & Stewart (1999) used a modified version of the Functional Behaviour Assessment for Children with Sensory Integrative Dysfunction (Cook, 1991) to assess the participants and reported improvements in social interaction, approach to new activities, response to movement and holding for two children with autism who received sensory integrative based occupational therapy for one hour per week for seven to eleven weeks. Additionally, neither of the boys exhibited self-stimulating behaviours but the second participant did not demonstrate gains in functional communication. In another study about a sensory-based intervention and autism from the USA Gee et al (2014) implemented a sound intervention in a 7-year-old child with autism. The authors utilized a repeated measures design and the procedure included listening to classical music with headphones over a 10-week period. A standard test to assess sensory over-responsivity along with a caregiver survey were used as outcome measures and based on the findings the researchers reported positive outcomes in the child's behaviour with respect to verbalization and self-stimulatory behaviours.

In all of the studies (Case-Smith & Bryan, 1999;Linderman & Stewart, 1999; Watling & Dietz, 2007 and Gee et al, 2014) it was reported that the Sensory Integrative based occupational therapy might have a positive effect for children with autism. It is difficult though to generalize the findings, as the sample sizes were very small and the positive outcomes might have been attributed to maturation of the children, occurrence of confounding interventions or to "generalised therapeutic attention" other than the treatment per se. Also, in two studies (Watling & Dietz, 2007 and Pfeiffer et al, 2011) there was insufficient information provided to identify the specific combination of intervention procedures used, which makes it difficult to replicate their findings.

McClure & Holtz-Yotz (1991) and Zisserman (1991) investigated the efficacy of Sensory Stimulatory treatment. McClure & Holtz-Yotz (1991) used elastic wraps (deep pressure applied by foam-padded splints on the arms) to effect behavioural changes to a 13-year old boy with autism who was admitted to a psychiatric inpatient facility and Zisserman (1991) used pressure gloves and vest to decrease sensory stimulating behaviours in an eight-year-old girl with autism. In both studies no information is given to us about the reasons why the particular children were chosen or about the sampling strategy. Furthermore, the studies discussed the use of different variations of touch pressure garments in order to reduce self-stimulatory behaviours. In the McClure & Holtz-Yotz (1991) study the sensory stimulatory treatment was also used to reduce self-injurious behaviour.

The results of the McClure & Holtz-Yotz (1991) study showed that the treatment proved to have positive outcomes, since a decrease in self-stimulation and self-injurious behaviours along with an increased ability to interact with others were noted. In the Zisserman (1991) study though, clinical improvements were identified using the pressure gloves but not using the pressure vest. Overall analysis of both studies (McClure & Holtz-Yotz, 1991 and Zisserman, 1991) would have to conclude that given the limitations of the studies, definitive conclusions about the efficacy of the treatment are limited. The shortcomings include the fact that the participants underwent other kinds of treatment during the same period; investigator biases and poor validity of the measures.

Delvin et al (2011), also investigated the effect of sensory-integration therapy and wanted to identify if this treatment contributed to the reduction of self-injurious behaviours. The treatment was developed by an occupational therapist and involved swinging, jumping, rocking on a therapy ball, wrapping in blanket, crawling, joint

compression, squeezing with bean bags, chewing a tube, and brushing. In addition, in this study the comparative effects of sensory-integration therapy and behavioural intervention (Applied Behaviour Analysis) were explored within an alternating treatments design, and a functional analysis was used to identify the variables maintaining the self-injurious behaviour. Self-injurious behaviour was measured through direct observation. It should also be noted that the treatments were alternated across everyday sessions. Similarly to the McClure & Holtz-Yotz (1991) study only one child with autism was included and no information about the reasons why the particular child was chosen is given.

Contrary to the results of the previous study (McClure & Holtz-Yotz, 1991) sensory-integration therapy did not reduce self-injurious behaviours. However, the Applied Behaviour Analysis proved to be more effective in reducing levels of self-injurious behaviour. The generalizability of the findings is limited by the single case nature of the study and the fact that the boy already had behavioural treatment at school prior the intervention, which might have affected the positive results of the behavioural intervention.

6.2.1 Summary

One study by Lang et al (2012), rated as strong level I evidence, concluded that there is not enough scientific evidence to support the use of sensory integration therapy for children with autism. Nonetheless, for outcomes related to the use of sensory integration therapy with children with autism, strong evidence from a small number of RCTs support positive impact on the overall development of children. For example, in the Pfeiffer et al (2011) study the sensory integration group displayed significantly fewer autistic mannerisms; Fazlioglu & Baran (2008) determined that the sensory integration therapy program positively affected the group of children that followed the

sensory integration therapy program and their autistic symptoms decreased; Schaaf et al (2013) supports the use of a sensory intervention for children with autism and Iwanaga et al (2014) showed that sensory integration therapy helped improve children's motor coordination and nonverbal cognition. The remaining studies of lower quality evidence presented with mixed or negative findings in regards to the effectiveness of sensory integration therapy with children with autism. Therefore, based on all of the findings it cannot be determined if it benefits children with autism.

Table 16. Sensory Integration Interventions

Study	Country	Sample	Type of treatment	Outcome Measures	Key findings
Fazlioglu & Baran (2008) Randomized control trial Level I evidence	Turkey	2 groups (control and treatment), each comprising 15 children with autism aged 7-11y	Intervention program based on "The Sensory Diet" vs regular special education classes	Sensory Evaluation Form for Children with Autism	The treatment group showed improvements in sensory problems
Iwanaga et al (2014) Pilot study Level I evidence	Japan	Children aged 2-6 y divided in sensory integration therapy group (n=8) and group therapy (n=12)	Sensory integration therapy (SIT) vs Group therapy	Japanese re-standardized version of Miller Assessment for Preschoolers	- Sensory integration therapy helped improve children's motor coordination and nonverbal cognition Both groups showed improvements
Lang et al (2012) Systematic review Level I evidence	USA	25 studies on the use of sensory interventions for children with autistic spectrum disorders	Sensory integration therapy (SIT)	Systematic review of the literature on SIT written between 1980-2011	- 3 studies reported positive effect of SIT - 8 studies reported mixed results - 14 studies suggested that SIT is not beneficial Evidence-base did not support the use of SIT with children with autism
Pfeiffer et al (2011) Randomized control trial Level I evidence	USA	37 children with autism or PDD-NOS, aged 6-12 y,	Sensory integration therapy (SIT) vs Fine motor treatment	SPM, SRS, QNST-II, GAS, VABS-2	- Positive gains in both groups - Sensory integration group displayed significantly fewer autistic mannerisms than the fine motor group
Schaaf et al (2013) Randomized control trial Level I evidence	USA	17 children with autism, aged 4-8 y	Manualized sensory intervention vs usual care	SIPT, GAS, PEDI, PDDBI, VABS-2	- Higher scores on the outcome variables after treatment - Decrease in the children's need for assistance regarding self-care and social activities
Bagatell et al (2010) Single-subject Level IV evidence	USA	6 boys with autism (kindergarten-1st grade)	Therapy ball chairs	Social validity questionnaire	- Ball chairs did not appear to be effective for all children - Positive effect only for the child that had the most extreme vestibular-

					proprioceptive-seeking behaviours
Case-Smith & Bryan (1999) Single-subject Level IV evidence	USA	5 boys with autism, aged 4-5 y	Sensory integration therapy (SIT)	Engagement Check	- Gains in mastery play and adult interaction along with decreases in non-engaged behaviours - No improvement in peer interaction
Devlin et al (2011) Single-subject Level IV evidence	Ireland	4 children with autism aged 6-11 y	Sensory integration therapy (SIT) Applied Behaviour Analysis	QABF, FAST-R	- Sensory-integration therapy did not reduce challenging behaviours and might have increased challenging behaviour in 1 child - ABA reduced challenging behaviour for all 4 participants
Gee et al (2014) Single-subject Level IV evidence	USA	7-year-old child with autism	Sound intervention	SPM, SensOR	- Positive outcomes in the child's behaviour with respect to verbalization and self-stimulatory behaviours -
Linderman & Stewart (1999) Single-subject Level IV evidence	USA	Two 3-year-old boys with PDD	Sensory integration therapy (SIT)	Cook's revised Functional behaviour Assessment for Children with Sensory Integrative Dysfunction	- Improvements in social interaction, approach to new activities, response to movement and holding - The second participant did not demonstrate gains in functional communication - Neither of the boys exhibited self-stimulating behaviours -
Marr et al, (2007) Single-subject Level IV evidence	USA	3 preschool children with autism	Sensory stories	SSP, Time Sampling Data Form	- Improvements in targeted behaviours - One child was already improving during baseline -
Sniezyk & Zane (2015) Single-subject Level IV evidence	USA	3 children with autism, aged 2-3 y	Sensory activities	Functional Assessment	- No clear functional relationship between positive changes in dependent measures and the application of a sensory intervention

Watling & Dietz (2007) Single-subject Level IV evidence	USA	4 children with ASD, aged 3-4 y	Sensory integration therapy (SIT)	Rating of videotaped sessions	- No significant improvement after SIT in undesired behaviour and engagement of the participants - Sensory integration had a positive effect on transitions, socialization, compliance and general behaviour regulation during the sessions and in the home environment
McClure & Holtz-Yotz (1991) Case report Level V evidence	USA	13-year old boy with autism	Sensory Stimulatory treatment	Clinical observations	- Decrease in self-stimulation and self-injurious behaviours - Increased ability to interact with others
Zisserman (1991) Case report Level V evidence	USA	8-year-old girl with autism	Pressure garments (vests and gloves)	Clinical observations	- Decrease in self-stimulating behaviours with gloves - Non-significant decrease in self-stimulating behaviours with vests

6.2.2 Weighted Vests

The use of weighted vests is one of the techniques used by occupational therapists when children with autism face sensory processing difficulties. A child must wear the weighted vest every day for certain periods of time. The vest usually weighs 1-4 lbs and the weight is evenly shared in pockets in the front and back vest panels (Olson & Moulton, 2004).

Nine studies (table 17) have investigated the effect of weighted vests in occupational therapy practice since 2000, and in most of them the findings did not support the use of the vest on children with autism.

Kane et al (2005); Reichow et al (2010) and Hodgetts et al (2011) evaluated the effects of weighted vests on behaviours considered to be self stimulatory or stereotypic. Kane et al (2005) measured four children on the autism spectrum. Three of the participants were diagnosed with autism and one with pervasive developmental disorder-not otherwise specified (PDD-NOS). Direct observation was used to measure stereotypic behaviours and attention to task during three phases: baseline, participant wearing a vest and participant wearing a vest with no weight. In order to improve controls the conditions were mixed in sequence. In the Reichow et al (2010) study the aim was to determine whether the use of a weighted vest would increase engagement in the content of a table-time activity. Observation through videos was used to measure engagement, stereotypic and problem behaviour. Similarly to the previous study (Kane et al, 2005) three different conditions were compared: weighted vest, vest with no weight (which served as placebo) and no vest (which served as a baseline). There were no improvements in the targeted behaviours in either study. In addition, in three of the participants in the Kane et al (2005) study negative outcomes were produced after wearing the vest. This highlights the fact that therapeutic interventions

are not always ‘neutral’ when they are ineffective.

In the Quigley et al (2010) study two children with autism and one child with Asperger’s participated. The aim of the study was to examine the effect of weighted vests during functional analysis conditions on problem behaviours in children with pervasive developmental disorders. Leew et al (2010) recruited four children with autism and used direct observation to measure joint attention and competing behaviours (problem behaviours that interfere with the child’s ability to play) after the use of weighted vests. The results showed that weighted vests did not decrease the rate of problem competing behaviours, nor improved joint attention, measured as functional, pre-linguistic social communication. Therefore, consistent with the previous studies (Kane et al, 2005 and Reichow et al, 2010) the use of weighted vests did not result in reductions in problem behaviour for any of the children with autism in the Quigley et al (2010) study, nor had a positive effect on the participants in the Cox et al (2009) and Leew et al (2010) studies. As seen in the Kane et al (2005) and Reichow et al (2010) studies three conditions (no vests, vests with no weight and weighted vests) were also compared in the Cox et al (2009) study. Three children with autism participated in this study and the purpose was to investigate the effect of weighted vests on in-seat behaviour. The findings suggested that the use of weighted vests did not increase the duration of appropriate in-seat behaviour. The use of small samples, biases and co-interventions in the above studies (Kane et al, 2005; Cox et al, 2009; Reichow et al, 2010; Quigley et al, 2010 and Leew et al, 2010) limited the results.

Given the lack of empirical evidence, it is interesting to explore whether this type of OT is in common use by therapists. Olson & Moulton (2004) conducted a survey of occupational therapists’ use of weighted vests. The survey was sent by mail

to a random sample of paediatric occupational therapists from the American Occupational Therapy Association's member database. A sample of 514 paediatric OTs gave positive responses in regards to improvements in children's on-task performance while wearing weighted vests, which contradicts previous empirical findings (Kane et al, 2005; Cox et al, 2009; Reichow et al, 2010; Quigley et al, 2010 and Leew et al, 2010). Also, the results showed that the respondents (82%) mostly used the weighted vests with children with autism. However, the validity of the results was limited by the fact that the participants were self-selected.

With the aim to explore the effects of weighted vests for children with autism Hodgetts et al (2011) conducted a small scale randomized controlled study. The sample in the Hodgetts et al (2011) study consisted of ten children with autism. The study took place at each child's self-contained classroom and observation through videos along with standardized questionnaires and subjective reports were used to measure the children's behaviours. Contrary to the findings of the study by Olson & Moulton (2004) no significant improvements were identified across all the participants in their behaviours following the application of a weighted vest. Some positive effects of the weighted vests were identified but not all targeted behaviours were affected in a positive manner. The results are weakened though by small sample size, the diversity in classroom setting (segregated and inclusive), and teaching and aide styles of interaction.

Two reviews (Stephenson & Carter, 2008 and Morrison, 2007) involving children with autism and other diagnoses have arrived at similar conclusions with the above studies (Kane et al, 2005; Cox et al, 2009; Reichow et al, 2010; Quigley et al, 2010; Stephenson & Carter, 2008 and Morrison, 2007 and Leew et al, 2010) regarding the effect of the use of weighted vests. In the Morrison (2007) paper five

studies were reviewed and it was suggested that there is limited evidence to support the effectiveness of the use of weighted vests with children with autism. Stephenson and Carter (2007) reviewed seven studies and reached the conclusion that weighted vests are ineffective. It was also argued in both reviews that most of the studies examining the use of weighted vests are methodologically weak. As it is mentioned by the authors most of the studies on weighted vests include a rather small sample size, the conditions in the studies are often not well controlled and interobserver reliability is either missing or inadequate.

6.2.3 Summary

The body of evidence to support the use of weighted vests for children with autism is low and inconsistent. Although, Olson & Moulton (2004) found that weighted vests are widely used with children with autism, research is limited regarding their effectiveness. Based on the studies with the strongest evidence rating (Stephenson & Carter, 2008 and Morrison, 2007) weighted vests have not been shown to have positive effects with children with autism.

Table 17. Weighted Vests

Study	Country	Sample	Type of treatment	Outcome Measures	Key findings
Morrison (2007) Review Level I evidence	USA	5 studies	Weighted vest vs	review of the literature on weighted vests from 1980-2006	Limited evidence to support the effectiveness of the use of weighted vests on children with autism.
Stephenson & Carter (2007) Review Level I evidence	Australia	7 studies	Weighted vest	review of the literature on weighted vests until 2007	- There is no consistency in the positive results of the wearing of weighted vests
Cox et al (2009) Single-subject Level IV evidence	USA	3 children with autism, aged 5-9 y	Weighted vest	rating of videotaped session	- Use of weighted vests did not increase the duration of appropriate in-seat behaviour
Hodgetts et al (2011) Single-subject Level IV evidence	Canada	10 children with autism, aged 3-10 y	Weighted vest	Polar Vantage XL heart rate monitor, rating of videotaped session	- Some positive effects of the weighted vests were identified but not all targeted behaviours were affected in a positive manner
Kane et al (2005) Single-subject Level IV evidence	USA	4 children on the autism spectrum	Weighted vest	Clinical observation	- No improvements in stereotypy and attention - Negative effect on 3 children
Leew et al (2010) Single-subject Level IV evidence	Canada	4 children with autism aged 27-33 mo	Weighted vest	rating of videotaped session	- No decrease in rate of problem competing behaviours, nor improved joint attention
Quigley et al (2010) Single-subject Level IV evidence	USA	2 children with autism and 1 child with Asperger's, aged 4-12 y	Weighted vest Functional Communication Training (FCT)	rating of videotaped session	- No reductions in problem behaviours

Reichow et al (2010) Single-subject Level IV evidence	USA	2 boys with autism, aged 5 y; one with developmental delay, aged 4 y	Weighted vest	rating of videotaped session	- No improvements in the targeted behaviour (engagement)
Olson & Moulton (2004) Survey Level V evidence	USA	514 paediatric OTs	Weighted vest	mail survey about paediatric occupational therapists' opinions and general practice patterns with weighted vests	Increases children's positive behaviours, e.g. on-task performance while wearing weighted

6.2.4 Aquatic Therapy and OT incorporating animals

Another technique that is used by occupational therapists is aquatic therapy. Aquatic therapists treat children with autism in the water environment. The elements of the water seem to provide relatively constant somatosensory input (Becker, 1997). Based on the work of Vonder Hulls et al (2006) the focus of aquatic therapy is on the initiation and maintenance of eye contact, increase of concentration and longer toleration of touch, which are needed in order to engage in everyday activities. Hall (2013) suggests that swimming is a calming sensory activity that can help children with autism advance their communication skills and positive behaviours.

With respect to the use of animal-assisted occupational therapy for children with autism it is suggested by Koegel et al (2005) that it is necessary to encourage children with autism to be more active in their therapeutic and learning processes by engaging them in the use of naturally motivating elements in the environment. However, research concerning the use of aquatic therapy and animal-assisted occupational therapy as effective interventions is limited and lacks robust scientific evidence.

Three studies (table 18) examine aquatic therapy and two studies focus on occupational therapy incorporating animals (table 18) that can be recognized as an adjunct to traditional occupational therapy.

Ennis (2011) investigated the efficacy of aquatic therapy and recruited six children with autism. The author used two standardized instruments; the Water Orientation Test Alyn (WOTA; Tirosh, 2011) was used to measure the children's adaptation to water and the PEDS-QL (Varni et al, 1999) was completed by the parents to assess quality-of-life issues. The author suggested that the treatment contributed to an increase in the children's social and communication skills and physical benefits were reported as well. However, the low sample size limited the

generalizability of the results. Pan (2010) used a controlled single-blind design to investigate the effect of a 10-week swimming program on 16 children with autism. Each child was assessed three times during a 21-week period; in the beginning, after the 10-week program and in the end of the study. The children were also divided into two groups (A and B); in the first 10 weeks group A was trained in the water exercise program whilst group B continued with their regular treatment and during the next 10 weeks the roles were reversed. The School Social Behaviour Scale was used by the participants' schoolteacher to assess the children's social behaviours and all classroom teachers were blind to the children's treatment conditions, when the assessment was carried out. Based on the findings the authors suggested that this type of aquatic program could have a positive effect on the aquatic skills and social skills, mostly for children with autism who have developmental and cognitive impairments.

Vonder Hulls et al (2006) conducted a survey to identify clinicians' perceptions of the impact of aquatic therapy for children with autism. The participants of the study were occupational therapists who had used aquatic therapy for at least one month to treat children with autism aged between four and ten years. Seventy-eight occupational therapists were approached from around the United States and they were selected through aquatic therapy networks and personal and business web sites. Of the 78 surveys nine were not returned, twenty-one were non-deliverable, thirty of the 48 aquatic therapists who returned the surveys did not treat children with autism between the required ages, so the results of the study were based on the responses of just eighteen clinicians. The survey that was developed by the authors consisted of three sections: the first focused on the eligibility of the therapists based on the inclusion criteria mentioned above, the second included questions about the length, duration, and frequency of the sessions, and about the ages of the children involved.

Finally, the third focused on the therapists' perceptions of the outcomes of aquatic therapy for children with autism. The results of the survey showed that half of the occupational therapists reported that children benefited from aquatic therapy in seven areas (swim skills, paying attention, muscle strength, balance, tolerating touch, eye contact and water safety). In addition, 80% of the participants identified a positive change in two areas (self stimulating behaviours and participation in water activities). However, the sample size was small and selective which limited conclusive statements along with participants' biases. Thus, it is probable that the therapists who volunteered to participate in the study were the ones that were more positive about the gains of this approach.

Animal-assisted-therapy involves the use of an animal in order to help decrease symptoms of autism (Mills & Marchant-Forde, 2010). A meta-analysis of animal-assisted-therapy was carried out by Nimer & Lundahl (2007). The 49 studies included in the meta-analysis were coded for effect sizes and moderator variables and four of the studies included participants with autism. It was reported that animal-assisted therapy might have a moderate positive effect on children with autism. Nonetheless, the lack of control groups and other methodological flaws in the animal-assisted-therapy literature prevent a firm conclusion about the effectiveness of this approach with children with autism.

Sams et al (2006) designed a pilot investigation in order to compare the effectiveness of occupational therapy based on standard techniques to occupational therapy incorporating animals with children with autism. Twenty-two children with autism participated in the study. The study was conducted over fifteen weeks and the aim was for each child to have one session of standard occupational therapy per week and one session of occupational therapy incorporating animals per week. However,

due to situational factors the number of sessions that the children received therapy varied between two and twelve sessions of each form of therapy which is a major shortcoming. Direct observation was used to measure the changes in the language and social interactions of the children involved in the study. Participants demonstrated significantly more social interactions and made more frequent use of language during occupational therapy incorporating animals. However, the therapists involved in the study were not blind to the purpose of the study and this could have biased the findings. Also, it should be noted that social interaction with animals was considered equal to social interaction with humans in the study, which is not a perception that is universally accepted.

6.2.5 Summary

There are limited studies throughout the literature examining the use of aquatics and animal-assisted therapy for children with autism and the majority of these are of moderate or low quality evidence. The study that had the strongest evidence rating was a meta-analysis by Nimer & Lundahl (2007) who reported that animal-assisted therapy might have a moderate positive effect on children with autism. Additionally, evidence from different studies has credited aquatic therapy with having various benefits for children with autism.

Table 18. Aquatic Therapy and OT incorporating animals

Study	Country	Sample	Type of treatment	Outcome Measures	Key findings
Nimer & Lundahl (2007) Meta-analysis Level I evidence	USA	49 studies	Animal-assisted-therapy	Systematic review of the literature on animal-assisted therapy from 1973-2004	- Positive effect on children with autism e.g. decrease of autistic symptoms
Pan (2010) Pre-post level Level III evidence	Taiwan	16 children with autism, aged 6-8 y	Aquatic therapy vs regular treatment	HAAR checklist, SSBS-2	- Positive effect of the swimming program on the aquatic skills - Decrease in antisocial behaviour problems - No increase in social competence behaviours -
Sams et al (2006) Non-randomized control trial Level III evidence	USA	22 children with autism, aged 7-13 y	Regular occupational therapy and occupational therapy incorporating animals	Behavioural rating form	- Increase of social interactions for the OT incorporating animals group - More frequent use of language during OT incorporating animals -
Ennis (2011) Case series Level IV evidence	USA	6 children with autism, aged 3-9 y	Aquatic therapy	WOTA test 1 and 2	- Increase in the children's social and communication skills and physical benefits -
Vonder Hulls et al (2006) Survey Level V evidence	USA	18 aquatic occupational therapists	Aquatic therapy	Mailing survey about clinicians' perceptions of the benefits of aquatic therapy for young children with autism	- Half of the occupational therapists reported that children benefited from aquatic therapy in seven areas (swim skills, paying attention, muscle strength, balance, tolerating touch, eye contact and water safety) - 80% of the participants identified a positive change in two areas (self stimulating behaviours and participation in water activities)

6.3 Summary

McBee et al (2012) state that occupational therapy is one of the most common types of therapy for pre-schoolers with autism spectrum disorders in the school setting (SLT: 92% and OT: 67%) and outside the school environment (SLT: 52% and OT: 38%). However, this review of the literature demonstrates that occupational therapists working with children with autism use different approaches in their practice, some of which have better evidence than others.

The studies included in this chapter focus on different approaches that occupational therapists use to treat children with autism. Only five of the reviewed studies (see table 16) on the use of sensory integration therapy suggested that sensory-based interventions could be beneficial for children with autism, whereas eleven reported mixed or negative results. Most of the studies that demonstrated positive results were at the lowest level of certainty or poorest scientific quality. For example, Linderman and Stewart (1999) used a non-experimental design, of two single cases and reported that their participants were receiving at the same time another intervention as well. There were exceptions to this, however, and Schaaf et al (2013) carried out a study that met rigorous research standards and found some positive results of the SIT with children with autism. Overall though, it is not clear if this type of treatment can be beneficial for children with autism.

Nine studies (see table 17) explored the use of weighted vests with children with autism. Most of the studies used fairly rigorous experimental designs (e.g. alternating treatments design) but the findings did not support the effectiveness of the use of the vest on children with autism. Only a few studies examined the effectiveness of aquatic therapy and therapy incorporating animals (table 18). The findings of these studies support the efficacy of the above techniques for children with autism, but

several methodological flaws found in the studies reviewed weakened the validity of the results.

According to Sackett et al (1996) in evidence based practice the strongest evidence is used to support a clinical approach. Randomized controlled trials and systematic reviews are perceived to be at the highest level of evidence. The findings of the studies reviewed here should be interpreted with a few limitations in mind, since most of them did not employ a randomized control design. Nevertheless, many of the studies provide stronger evidence than those reported in the psychodynamic/psychoanalytic psychotherapy literature in Chapter 5. The studies exploring the use of occupational therapy with children with autism included larger sample sizes and the results were not based solely on the investigators' clinical observations, as in most of the studies in Chapter 5.

Given the growing number of children diagnosed with autism and the fact that occupational therapy is considered to be one of the most common types of treatment for children with autism it is important to promote research that investigates the effect of occupational therapy on children with autism. As suggested by Bagatell & Mason (2015) there should be more rigorous and high quality intervention studies conducted by occupational therapy researchers in order to contribute to the evidence base and identify the most effective treatments for children with autism.

Chapter 7 Research Design and Methods

7.1. Introduction

This chapter describes the methodological approach followed in the study. The aim of the chapter is to provide a critical discussion of the methodology, methods and ethical issues related to the study. The context of the settings will be outlined and the research design, methods and procedure will be described.

As outlined in Chapter One the purpose of the study is to explore childhood autism in the UK and Greece. The aim is to monitor the progress of children with autism over time and to explore the differences and similarities in the patterns of development of children with autism across the different therapies and across countries. The purpose of conducting a cross-national and longitudinal research study is also discussed in this chapter along with the justification of the selection of the UK and Greece, more specifically the cities of London and Thessaloniki.

7.2 Research Design

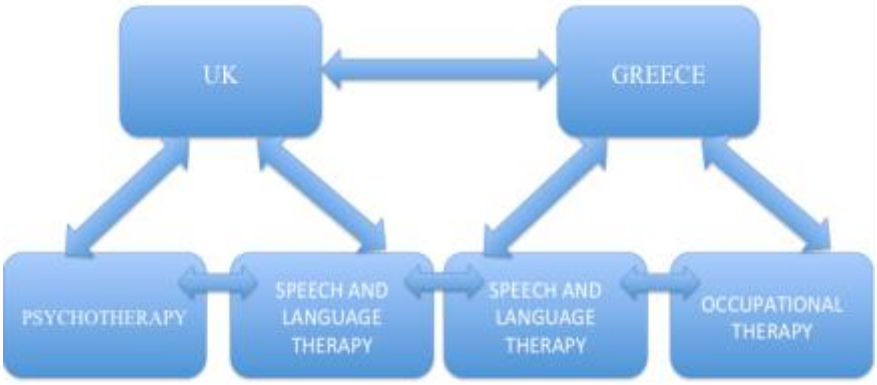
This study has a cross-national longitudinal design (Figure 1). A mixed (between-subjects and within-subjects) design was used to examine the relationship between the variables. The similarities and differences in the outcomes of speech and language therapy and psychotherapy in the UK and the outcomes of speech and language therapy and occupational therapy in Greece are explored over time along with the similarities and differences across countries for speech and language therapy.

Longitudinal studies of autism are usually carried out in one country to assess change within a specific context. However, as commented by Schuller et al (2012) when one conducts a cross-national study the benefits are that the findings can be replicated cross-nationally. In this study the purpose of conducting a cross-national

study is to explore the processes that construct national differences in the treatment of childhood autism, and to identify and discuss how childhood autism develops in the two countries. The importance of doing a cross-national study is that one can see the phenomenon in a broader international perspective, which can reveal the differences as well as similarities in the manifestation of childhood autism across countries.

This study also has a longitudinal design as it involves repeated measures of the same children over time. Longitudinal research measures prevalence at different time points and offers information on causation, prognosis, stability and change (Sanson et al., 2002). Longitudinal studies enable researchers to detect change in individuals or their environments from one data point to the next (Hunter et al., 2002).

Figure 1



7.3. The UK and Greece

In cross-national research the first and most challenging task is to select the countries where the research is to be carried out (Karatasios, 2008). As stated by Doran (2002) before conducting a cross-national study it is helpful to gain as much

knowledge of the two countries. This includes the healthcare context, the culture and the population to be studied.

As already mentioned in Chapter One an important rationale for selecting these two countries is that there are no other cross-national studies exploring the progress of children receiving different therapies for childhood autism in these two countries over time. There is also a growing need to extend the literature with respect to autism in Greece. This study is aiming to add to the limited knowledge that currently exists on this topic in Greece.

Moreover, it is relevant to add that both London and Thessaloniki were good locations for recruitment since there were private centres specialized in the specific types of treatment included in the study. With respect to practical reasons it is worth mentioning that the researcher has professional experience and knowledge of services for childhood autism in the cities of London and Thessaloniki, speaks both Greek and English and the researcher was a student at the City University London whilst conducting the research.

7.4 Research Settings

The services where the research was conducted were private practices and centres in both countries. In London the participants of the speech and language therapy group came from a private practice that provided speech and language services. The psychotherapy group came from a private centre that provided mainly psychodynamic/psychoanalytic services and specializes in childhood autism. In Thessaloniki the participants were recruited from a private centre that provides both speech and language services and occupational therapy services.

To better understand the context of the services where the research was conducted, the therapists in both countries were asked to complete a questionnaire (Appendix I). The questionnaire was not pilot-tested since it was only used as a tool to explore the research settings and gain a better understanding of their aims when working with children with autism. More specifically, it included 23 questions. The questions related to information about the assessments conducted as well as approaches and techniques used by the therapists. Namely, questions 1-3 served as a partial indicator of the type of assessment and approach followed by each clinician; questions 4 and 5 focused on the involvement of other professionals from different fields; questions 5-9 related to information about the characteristics of each intervention including parental involvement; questions 10 and 11 referred to the progress of the children as seen by the clinicians and finally the aims and specific treatment techniques used by each service provider were addressed by questions 12-22.

When asked to describe their techniques, the involved therapists listed a range of intervention techniques such as TEACCH and PECS to specific strategies. For example, the private practice that provided psychotherapy in London responded that their strategy is to explore the world from the perspectives of both the child and the family and that they work altogether with the whole family.

The services involved may provide different types of therapy but there are common areas that they all work on. With respect to the language and cognitive area they all focus on the children's interaction and communication skills, conversation skills, the child's capacity for self-expression and their ability to reason and problem solve; in the area of bevahiour and physical skills all practices target behaviour management and in the social and emotional area there is a common goal among

services to improve children's social skills, play skills and help them manage their stress. In regards to the main differences among services the speech and language services in both countries seem to target more the development of speech; the occupational therapy practice addresses more the children's sensory difficulties along with their gross/motor skills compared to the other types of therapy and the psychotherapeutic service seems to focus more on the development of the child's emotional skills and imagination through play. In the speech and language therapy practices between the two countries it can be seen in table 19 that they mostly focus on similar areas, like vocabulary, conversation skills, speech development etc. Nonetheless, the speech and language therapy practice in London seems to offer a wider range of techniques and strategies with respect to children's social/behavioural skills and autism diagnostics.

Collaboration with the parents was also an essential component of all of the services included in the study. The responses to the questionnaire, reported in Table 19, provide a description of service providers' reports of their use of specific treatment practices in intervention programmes for children with autism. It is useful to understand how service providers implement their programmes, in order to get a fuller picture of their treatment plans and the specific areas they target (Table 19).

Table 19. Findings from the Questionnaire

	LANGUAGE / COGNITIVE	BEHAVIOUR / PHYSICAL	SOCIAL / EMOTIONAL
SLT-GR	**Focus on:** speech development, descriptive and communicative language, vocabulary, syntax, articulation, prosodic features, interaction & communication skills, receptive language skills, conversation skills, the child's capacity for self expression and to reason and problem solve	**Focus on:** self-care activities and behaviour management	**Focus on:** play skills, social skills, stress management
OT-GR	**Focus on:** cognitive skills, interaction & communication skills, use and understanding of body language and facial expressions, conversation skills, the child's capacity for self expression and to reason and problem solve	**Focus on:** gross/motor skills, behaviour control/self control, sensorial integration, praxis, everyday activities, the quality of child's interactions, the child's ability to cope with everyday situations, the child's understanding of social cues and conventional behaviour, sharing and taking turns, self-care activities	**Focus on:** play skills, social skills, the child's awareness of their difficulties and emotions, stress management
PSYCHOTHERAPY-UK	**Focus on:** communication interaction and communication skills, receptive language skills use and understanding of body language and facial expressions, conversation skills, higher level of language skills (e.g. humour), the child's capacity for self expression and to reason and problem solve	**Focus on:** sensorial area, the quality of child's interactions, the child's ability to cope with everyday situations, the child's understanding of social cues and conventional behaviour, sharing and taking turns, behaviour management	**Focus on:** social and emotional skills, play skills, imagination, the child's awareness of their difficulties and emotions, stress management
SLT-UK	**Focus on:** speech (phonology), auditory processing, expression, understanding, pragmatics, fluency, speech, non-verbal language, social and cognitive skills vocabulary, syntax, semantics, articulation, prosodic features, abnormal/repetitive use of language, interaction and communication skills, receptive language skills, use and understanding of body language and facial expressions, conversation skills, higher level of language skills (e.g. humour), the child's capacity for self expression and to reason and problem solve	**Focus on:** Behaviour management	**Focus on:** play skills, social skills and stress management

7.5 Participants

Twenty children with autism who completed one of two differing types of treatment in the UK (psychotherapy, n=10 and speech and language therapy, n=10) were recruited to be monitored post-therapy twice over a two-year period. Twenty children with autism that received one of two types of treatment in Greece (occupational therapy, n=10 and speech and language therapy, n=10) were also recruited to be monitored post-therapy twice over a two-year period. This sample size is similar or greater to other studies in this field of research (Hayward et al, 2009; Moore and Goodson, 2003; Charlope-Christy et al, 2002; Vorgraft et al, 2007; Sherkow, 2011; Iwanaga et al, 2014)

The therapists in both countries were asked to identify children who met the following criteria:

- diagnosis of autism or autistic symptoms before being involved in any kind of treatment.
- to be aged from 2.5 to 10 years.
- non-verbal cognitive abilities to be in the low to normal range.
- to be either monolingual or bilingual.

Also, the therapists in both countries were asked to exclude children:

- with concomitant deafness.
- with epilepsy.
- with visual impairment.
- receiving another one of the studied therapies intensively.
- receiving medication.

The final sample consisted of 40 children with autism that were assessed at time point one: Ten children receiving speech and language therapy and ten receiving

psychotherapy in the UK; ten children receiving occupational therapy and 10 children who had speech and language therapy in Greece. Two of the children in the speech and language therapy group in the UK were not available for the second assessment due to personal reasons meaning that in year two, their data is not available. Additionally, the demographics were not significantly different among groups. A one-way analysis of variance was conducted between groups on age and the results ($F(3,37)=1.084$, $p=0.36$) showed that there was no significant difference. Also, chi-square tests were performed and no significant differences were found between groups on gender (χ^2 $(3)=2.165$, $p=0.58$) nor on severity of autism symptoms (χ^2 $(3)=3.643$, $p=0.30$). Table 20 shows a breakdown of the numbers in each group at time point one and table 21 shows a breakdown of the numbers in each group at time point two.

Table 20. Sample of children who participated in the study at time 1

UK		**GREECE**	
Speech and Language Therapy **N=10** **9 male/1 female** **5 low functioning children** **Mean age=75.90m** **Min=37m/Max=108m** **(SD=24.6)**	**Psychotherapy** **N=10** **8 male/2 female** **4 low functioning children** **Mean age=60m** **Min=30m/Max=102m** **(SD=27.7)**	**Occupational Therapy** **N=10** **10 male** **5 low functioning children** **Mean age=59.30m** **Min=39m/Max=96** **(SD=18.01)**	**Speech and Language Therapy** **N=10** **9 male/1 female** **2 low functioning children** **Mean age=68.50m** **Min=45m/Max=98** **(SD=16.11)**

Table 21. Sample of children who participated in the study at time 2

UK		GREECE	
Speech and Language Therapy	**Psychotherapy**	**Occupational Therapy**	**Speech and Language Therapy**
N=8	**N=10**	**N=10**	**N=10**
7 male/1 female	**8 male/2 female**	**10 male**	**9 male/1 female**
Mean age=85.87m	**Mean age=71.4m**	**Mean age=70.6m**	**Mean age=79.7m**
(SD=23.6)	**(SD=27.58)**	**(SD=17.28)**	**(SD=16.8)**

7.6 Ethical Considerations

Ethical approval for this study was granted by the School of Health Sciences Research Ethics Committee at City University London (Appendix II). Parents were all given a Participant Information Sheet (Appendix III) and they were asked to sign a Participant Consent Form (Appendix IV) prior to the assessments. Meanwhile, the procedures were also explained verbally, in easy to understand language, to children with autism.

With respect to the processing of personal data, the privacy of the participants was respected and the confidential nature of the study was communicated to all participants, parents, carers and others involved in the study. All the participants were informed that the data from the study would only be used for the sole purpose of this research project. They were also informed that their identity will be protected and their name, address or other personal information would not be used for the purpose of the study. All participants were identified by a number and their real names were not used to identify them in order to ensure confidentiality of participants. Moreover,

the hard data were stored in a secure place in a locked cabinet and electronic data were stored on a password-protected computer.

7.7 Procedure

The selected services in London and Thessaloniki were approached regarding the recruitment of families for the study. In the following sections the procedure followed in both countries will be discussed.

7.7.1 Thessaloniki

In Thessaloniki, a Child Neurologist known to have an interest in childhood autism was approached in order to identify suitable services in Thessaloniki; subsequently an introduction to a private centre that provided both speech and language therapy and occupational therapy was initiated. The occupational therapist and the speech and language therapist were contacted, the study was described and they agreed to take part in the research and refer children from their caseloads. The therapists sent out an information letter (approved by City University London Research Ethics Committee) to the families attending their practice that included the aims, the content and rationale of the study along with the procedures that would be undertaken (see appendix III). Following these letters, the occupational and speech and language therapists scheduled an initial discussion appointment between the parents and the researcher. During the appointment (described in section 7.6) any queries with respect to the research were answered and the parents signed a consent (Appendix IV) form (no parents declined at this stage). In addition, the appointments for the assessments were scheduled.

According to Flewitt (2005) sometimes parents may feel obliged to accept the invitation to participate in a study because they fear that if they deny the therapeutic

process of their children might change and they could be negatively affected. Therefore, it is recommended that researchers assure parents that their choice will not affect the services they attend and that they clarify the situation. In the current study this issue was considered, hence the meeting and the informed consent provided to the parents prior to the start of the study.

The children from both the occupational therapy group and the speech and language therapy group were assessed individually in a room in the centre where they had therapy and their parents completed the relevant questionnaires in the same room after their children completed the tests. The testing was conducted over two sessions that lasted about an hour each. During the first session the ADOS and the SCQ were implemented and upon the second visit the rest of the tests were provided.

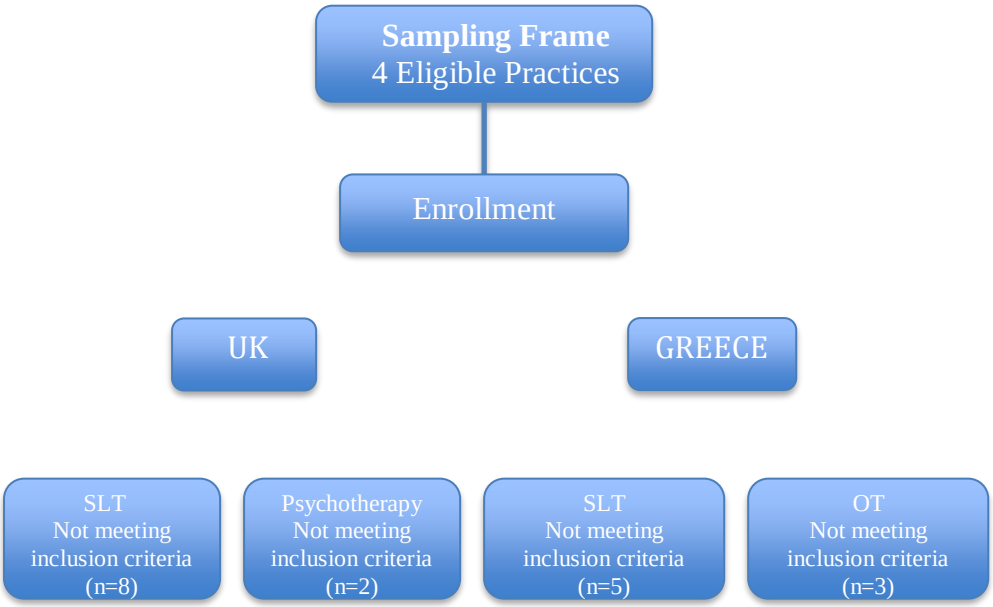
7.7.2 London

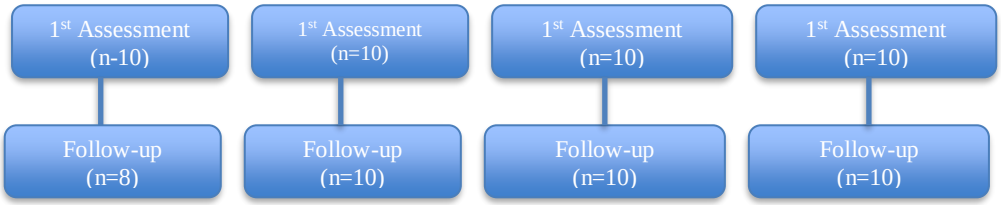
The first step in the recruitment of participants in London was to approach a private psychotherapeutic centre and a private practice that offered speech and language therapy. A child psychotherapist who was a contact of the researcher and runs a private centre providing psychodynamic/psychoanalytic services was initially contacted and agreed to take part in the research and refer children from their caseloads. With respect to the speech and language therapy practice the search was more complicated. A request for services to participate in the study was circulated via email or telephone calls. In total about twenty private settings were contacted. Some of these services were not interested and others invited families to participate but the families were not interested. Eventually, one of the clinicians who had been approached agreed to invite families from their private practice.

The next steps were similar to the procedure followed in Thessaloniki. Each service sent out an information letter to the families from their practice that included the aims, the content and rationale of the study along with the procedures that would be undertaken. Following the letters, the researcher scheduled an introductory appointment with the families. During the appointment any queries with respect to the research were answered and the parents gave written consent. Finally, the appointments for the assessments were scheduled.

The children from both the groups were also assessed individually in a room in the service where they had therapy and their parents completed the relevant questionnaires in the same room after their children completed the tests. The testing was conducted over two sessions that lasted about an hour each. During the first session the ADOS and the SCQ were implemented and upon the second testing session the rest of the assessments were carried out.

Figure 2. Recruitment





7.8

Assessment Measures

As it was previously discussed in chapter 1, autism is considered as a highly complex disorder that affects social communication, social interaction and imagination (triad of impairments) in individuals and might hinder the development of their social, language and cognitive skills (Filipeck et al., 1999). Also, as it is suggested by the current diagnostic criteria DSM 5th edition (DSM-5, APA, 2013) children with autism often present with restricted interests or repetitive behaviours. Therefore, our aim was to find measures that assess all these areas of deficit and the search for assessment measures was guided by our need to find tools that have been used in Greece as well. In addition, as it was mentioned in section 7.4 some of the therapeutic goals that each practice sets are different from each other, so the assessment measures needed to reflect each therapy's focus as well. Thus, by looking across country and context it was concluded that there were limited measures that matched our criteria.

All measures were completed by the parents and via direct testing with the children. Non-standardized Greek versions of all the tests were used for the Greek sample. The author translated all the tests prior to the assessments. Personal communication and advice from researchers experienced in using non-standardized Greek versions of the CELF , BPVS and CDI (Stavrakaki & Van der Lely, 2010; Kambanaros et al, 2015) suggested that for the tests used here this raised no significant translational issues. This is largely because the materials are at the single word level within this study.

The following measures were employed:

Autism Diagnostic Observation Schedule (ADOS; Lord et al, 2000)

The Autism Diagnostic Observation Schedule is a semi-structured standardized observation of the child that measures autism symptoms in social relatedness, communication, play (imagination), and repetitive/stereotypic behaviours. As part of the schedule, planned social occasions, referred to as "presses" (Lord et al, 1989) are created in which a range of social initiations and responses is likely to appear. Similarly, opportunities to communicate are created in order to evoke a range of interchanges. Various play situations are facilitated aiming to allow observation of a range of imaginative activities and social-role play (Lord, 2000). Another aim of the ADOS is to provide presses that draw out spontaneous behaviours. The schedule consists of four modules and each one is appropriate for children and adults at different developmental and language levels. Each module lasts about 30-45 minutes and only one is administered to each individual, based on the individual's developmental and language levels. ADOS items are typically scored on a 3-point scale from 0 (no evidence of abnormality related to autism) to 2 (definite evidence). Some of the items include a code of 3 suggesting severe abnormalities that might interfere with the observation. Throughout the analyses, scores of 3 are converted to 2. Moreover, the scores are compared with an algorithm cut-off score for autism or more broadly defined ASD (Lord et al, 2000). The ADOS has the most empirical support among observation based diagnostic assessment procedures for autism and is recommended in several best practice guidelines as an appropriate standardized diagnostic observation test (Wilkinson, 2010). The ADOS was not used as a diagnostic measure but as a tool to assess symptoms.

Social Communication Questionnaire (SCQ; Rutter et al, 2003)

This is a 40-item binary scaled screening instrument for autism to be completed by parents. In non-verbal children 6 items are left out. The points are summed and the cut-off is established as ≥22 for autism and ≥15 for ASD (Oosterling et al, 2010). The SCQ is broadly used to screen for autism spectrum disorders and has established comparative validity against the Autism Diagnostic Interview-Revised (ADI-R; Lord et al, 1994). Also, it has been recently reported as the most effective assessment tool for autistic symptoms (Charman et al, 2007).

Raven's Coloured Progressive Matrices (Raven, 2003)

A child-based measure of non-verbal cognitive ability often used in studies of children with language impairment due to its easy and quick administration, lack of timed tasks, and non-verbal nature. The Ravens Matrices include a series of diagrams or designs with a part missing. Each individual is supposed to choose the correct part to complete the designs among a variety of options printed beneath (Raven, 2003). The test consists of 36 matrices divided equally into 3 sets (A,AB,B). In each matrix, there are 6 choices. The correct answer is given one score and the wrong is given zero, which means that the raw score on the test ranges between zero to 36. Ravens Matrices have been used broadly in various settings across countries as a measure of non-verbal intelligence (Kazem et al, 2009). Reliability data was presented in the 1986 Raven manual showing adequate reliability for research purposes and validity evidence extends primarily from correlational studies with other tests (Kamphaus, 2005).

MacArthur-Bates Communication Development Inventory (CDI; Fenson et al, 2006)

The CDI is a well used and standardised parent based checklist measure of vocabulary understanding and use. It contains 416 standard words for which both comprehension and

production are assessed. With respect to the validity of the CDI, studies have demonstrated substantial correlations between scores on a variety of parent-report measures and scores on measures from concurrent language samples and structured tests (Feldman et al, 2005).

Clinical Evaluation of Language Fundamentals (CELF IV – Semel et al, 2003)

The CELF is a child-based standardised language assessment. It provides a flexible, multi-perspective assessment process for pin-pointing a child's language and communication strengths and weaknesses. Two subtests were used: Formulating Sentences (FS-production) and Concepts and Following Directions (C&FD-comprehension). In the Concepts and Following Directions the child points to pictured objects in response to oral directions and in the Formulated Sentences the child formulates a sentence about visual stimuli using a targeted word or phrase. The CELF has showed high correlation rating with similar instruments and its validity has been established through factor analyses, review of literature and analyses of response process (Semel et al, 2003).

British Picture Vocabulary Scale II (BPVS II; Dunn et al,1997)

This is a child-based measure, which is used as a test of word knowledge or vocabulary comprehension and is brief and easy to administer. The child being tested needs only to point to a picture and does not have to be able to read, write or speak. It is a test of receptive vocabulary and it is administered individually and provides norm-referenced scores. Raw scores are converted into an age equivalent score in years and months. Also, the scale has good reliability and validity (Glenn & Cunningham,2005).

7.9 Data Analysis

The data were analysed using SPSS. The aims were addressed by using: repeated-measures ANOVAs to assess differences in skill level across countries and across therapies; repeated-measures ANOVAs to assess progress over time for the whole group; mixed ANOVAS (2 groups: between x 2 time points: within) to assess differential change following different therapy types / different country of service user. Correlational and regression measures were used to explore associations with degree of progress within groups. ANCOVA analyses were also employed for progress data where analysis revealed significant baseline characteristics between the groups. When data proved not to be robust enough for parametric analysis, non-parametric equivalents were used where possible.

7.10 Summary

This chapter has outlined the research design and methods employed for this research involving families of children with autism in the UK and in Greece. A cross-national longitudinal design and a mixed (between-subjects and within-subjects) design were utilized in order to address the aims of the study. This chapter also reported on the procedure and the ethical considerations of research with children and their parents.

Chapter 8 Results

In this chapter the findings will be presented in 4 main sections:

i) Exploration of association between skills and their developmental trends over time for the whole group (regardless of country or intervention background)

ii) Examination of the effects of country (regardless of intervention context) on change over time (country and intervention considered simultaneously)

iii) Examination of development across different countries (all children and when intervention context is held constant, i.e. just SLT groups)

iv) Subgroup analysis of the effect of country on those with the same therapy context (SLT); and the effect of therapy context on children in the same country.

Because of the wide age range represented in the sample, and because the initial age of the child might affect rate of development, ANCOVAs have additionally been run on section 8.4 analysis with age as a covariate.

As it is seen below the descriptive details of the baseline data by country are presented in table 22. See Appendix V for the individual participant data at time 1. Based on the data at time 1 the CDI scores seem to be high from the very beginning, which was somewhat expected because it is usually used to assess younger children. The reasons why it was chosen as an assessment measure are considered later in section 8.4. The results of the one-way ANOVAs (table 23) between the 4 groups are also provided here in order to explore any potential differences between the groups at baseline. The results showed that there were no significant differences between the different participant groups. This tells us that the children were similar at baseline, which makes it easier to monitor their progress over time and look into the factors that migh have influenced the development of the children's skills.

Table 22. All groups at time 1-descriptive details

Greece - Time 1

	SCQ1	ADOS-Com1	ADOS-Soc1	ADOS-Imag1	ADOS-Ster1	C&FD1	FS1	BPVS1	Raven1	CDI-U1	CDI-U/S1
SLT	10.8 (SD=3.39)	4 (SD=1.33)	4,7 (SD=2.21)	1,2 (SD=.63)	3,1 (SD=1.20)	20,90 (SD=12.85)	12,30 (SD=9.58)	44.80 (SD=20.33)	10,80 (SD=6.30)	412,20 (SD=8.13)	374,70 (SD=101 .30)
OT	13.5 (SD=7.40)	5.20 (SD=2.04)	6,40 (SD=3.89)	1,50 (SD=1.35)	3,70 (SD=1.90)	12,70 (SD=8.69)	7.40 (SD=7.76)	37 (SD=23.92)	9.70 (SD=9.27)	362.50 (SD=109.6)	325.10 (SD=142. 03)

UK – Time 1

	SCQ1	ADOS-Com1	ADOS-Soc1	ADOS-Imag1	ADOS-Ster1	C&FD1	FS1	BPVS1	Raven1	CDI-U1	CDI U/S1
PSYCH	13.40 (SD=8.05)	5.90 (SD=3.573)	7.30 (SD=3.945)	1.60 (SD=1.265)	3.40 (SD=1.955)	13.50 (SD=18.241)	10.20 (SD=15.361)	41.00 (SD=30.166)	11.70 (SD=11.33)	393.60 (SD=39.48	301.80 (SD=150.103)
SLT	13.63 (SD=4.897)	5.88 (SD=1.885)	7.38 (SD=3.335)	2.25 (SD=1.165)	2.63 (SD=1.996)	15.88 (SD=9.717)	6.50 (SD=8.944)	39.50 (SD=22.860)	11.88 (SD=8.167)	416.00 (SD=0.00)	307.25 (SD=157.197)

Table 23. Comparison between groups at time 1

Measure	Group
Social Communication Questionnaire	F(3,37)=0.453,p=0.717
ADOS - Communication	F(3,37)=1.345,p=0.276
ADOS - Social	F(3,37)=1.269,p=0.301
ADOS - Imagination	F(3,37)=1.308,p=0.288
ADOS-Stereotypical behaviour	F(3,37)=0.591,p=p=0.625
Concepts and Following Directions (CELF)	F(3,37)=0.796,p=0.505
Formulated Sentences (CELF)	F(3,37)=0.550,p=0.651
British Picture Vocabulary Scale II	F(3,37)=0.174,p=0.914
Raven's Coloured Progressive Matrices	F(3,37)=0.116,p=0.950
MacArthur CDI – no of words understood &produced	F(3,37)=0.562, p=0.644

8.1 Development of children with autism over time

First we examined the relationship between the different measures in the group as a whole. The correlations between measures at time 1 revealed that most of the measures correlate with one another especially the ones that are used to assess the same areas (e.g., language). Moreover, three of the ADOS subscales correlated particularly highly with other skills but it should be noted that the CDI-U (no of words understood but not yet produced) did not correlate as strongly across the different measures (see Table 24 for details).

Table 24-Correlations

		ADOS-Comtime1	ADOS-Soctime1	ADOS-Imagtime1	ADOS-Stertime1	CFDtime1	FStime1	BPVStime1	Raventime1	CDI-Utime1	CDI-U/Stime1
SCQtime1	Pearson Correlation Sig. (2-tailed|) N	.693** .000 38	.753** .000 38	.590** .000 38	.683** .000 38	-.480** .002 38	-.367 .024 38	-.396* .014 38	-.416** .009 38	-.321* .050 38	-.503** .001 38
ADOS-Comtime1	Pearson Correlation Sig. (2-tailed|) N		.768** .000 38	.458** .004 38	.557** .000 38	-.661** .000 38	-.632** .000 38	-.556** .000 38	-.500** .001 38	-.096 .566 38	-.551** .000 38
ADOS-Soctime1	Pearson Correlation Sig. (2-tailed|) N			.678** .000 38	.744** .000 38	-.469** .003 38	-.389* .016 38	-.425** .008 38	-.455** .004 38	-.143 .391 38	-.594** .000 38
ADOS-Imagtime1	Pearson Correlation Sig. (2-tailed|) N				.531** .001 38	-.322* .049 38	-.275 .095 38	-.390* .015 38	-452** .004 38	-.155 .352 38	-.506** .001 38
ADOS-Stertime1	Pearson Correlation Sig. (2-tailed|) N					-.280 .089 38	-.266 .107 38	-.288 .080 38	-.313 .056 38	-.223 .178 38	-.420** .009 38
CFDtime1	Pearson Correlation Sig. (2-tailed|) N						.881** .000 38	.903** .000 38	.764** .000 38	.391* .015 38	.605** .000 38
FStime1	Pearson Correlation Sig. (2-tailed|) N							.846** .000 38	.740** .000 38	.398* .013 38	.557** .000 38
BPVStime1	Pearson Correlation Sig. (2-tailed|) N								.797** .000 38	.381* .018 38	.701** .000 38
Raventime1	Pearson Correlation Sig. (2-tailed|) N									.442** .005 38	.629** .000 38
CDI-Utime1	Pearson Correlation Sig. (2-tailed|) N										.264 .109 38
CDI-U/Stime1	Pearson Correlation Sig. (2-tailed|) N										

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

In the second part of this analysis, the development of the sample as a whole was explored. Repeated measures ANOVAs revealed that the children (n=38) changed significantly over time on all aspects of measurement. Of particular interest is that as a group, strong developmental trends can be seen in the level of autistic features noted on the ADOS scales (see table 25 for details). This is somewhat expected since development is rarely static. Nevertheless, some of the tasks used were designed for younger children and it remained uncertain as to whether these would show development in this older age group. In addition, the measures are raw scores and the group represents a wide age range.

Table 25. Development of the sample as a whole (n=38)

Measure	Time	Mean (SD)	Statistics
Social Communication Questionnaire	Time 1 Time 2	12.79 (SD=6.156) 11.34 (SD=5.409)	F(1,34)=12.899, p=0.001
ADOS- Communication	Time 1 Time 2	5.21 (SD=2.418) 4.21 (SD=2.373)	F(1,34)=30.962, p< 0.001
ADOS - Social	Time 1 Time 2	6.39 (SD=3.461) 5.18 (SD=2.940)	F(1,34)=44.026, p<0.001
ADOS - Imagination	Time 1 Time 2	1.605 (SD=1.151) 1.18 (SD=0.982)	F(1,34)=17.254, p<0.001
ADOS-Stereotypical behaviour	Time 1 Time 2	3.24 (SD=1.747) 2.58 (SD=1.638)	F(1,34)=19.956, p<0.001
Concepts and Following Directions (CELF)	Time 1 Time 2	15.74 (SD=12.977) 21.37 (SD=14.240)	F(1,34)= 74.984, p< 0.001
Formulated Sentences (CELF)	Time 1 Time 2	9.24 (SD=10.716) 12.58 (SD=12.324)	F(1,34)=9.942, p=0.003
British Picture Vocabulary Scale II	Time 1 Time 2	40.63 (SD=23.845) 51.68 (SD=24.495)	F(1,34)=82.843, p<0.001
Raven's Coloured Progressive Matrices	Time 1 Time 2	10.97 (SD=8.688) 14.92 (SD=9.601	F(1,34)=22.021, p<0.001
MacArthur CDI – no of words understood	Time 1 Time 2	342.24(SD=137.55) 400.89 (SD=65186)	F(1,34)=8.072, p=0.008
MacArthur CDI- no of words understood &produced	Time 1 Time 2	328.26 (SD=135.75) 379.05 (SD=88.486)	F(1,34)=15.137, p<0.001

8.2 Development of Greek children and English children

In this analysis, the progress of the children in the different resident countries (Greece, n=20 and the UK, n=18) was compared over time. Mixed 2 (group) x 2 (time) ANOVAs were completed on the various outcome measures. The overall pattern of these revealed few effects – the children changed significantly over time on all aspects of measurement but there was one group difference and a few significant interactions. All measures showed change over time and only the CDI-no of words understood (CDI-U) showed a main effect of group. More specifically, the children in Greece seem to have scored higher in the CDI-U. Also, the ADOS-Social (Figure 3); ADOS-Imagination (Figure 4); CDI-U (Figure 5) and the CDI-no of words understood and produced (CDI-U/S) (Figure 6) showed a significant interaction effect. The figures suggest that children in the UK improve faster in the areas of social skill, imagination and the CDI-U/S showed an increase in their ability to understand and say words compared to the children in Greece. However, the CDI-U showed that the children in Greece improved faster in the area of comprehension. It should be taken into consideration though that the scores of the children from the UK might have reached ceiling. See Table 26 below for the descriptive details and Table 27 for the statistical details. It should be noted that the values in table 26 differ from the ones presented in the graphs because all the participants from Greece (n=20) and all from the UK (n=20) at time 1 are presented in table 26 but in the figures the data of the two participants that dropped out from the UK group at time 2 were taken out pairwise by the ANOVAS. Additionally, the effect sizes were calculated for all significant interactions and as it can be seen in table 28 a moderate effect size was determined, that reflects a medium effect.

Table 26. Comparison of the progress of the children in the different resident countries-descriptive details

Time 1

	SCQ1	ADOS-Com1	ADOS-Soc1	ADOS-Imag1	ADOS-Ster1	C&FD1	FS1	BPVS1	Raven1	CDI-U1	CDI-U/S1
GREECE	12.15 (SD=5.77)	4.60 (SD=1.78)	5.55 (SD=3.20)	1,35 (SD=1.040)	3,40 (SD=1.56)	16.80 (SD=11.47)	9.85 (SD=8.85)	40.90 (SD=21.97)	10,25 (SD=7.73)	287.05 (SD=170.94)	349.90 (SD=122.73)
UK	11.60 (SD=6.202)	4.55 (SD=2.012)	5.40 (SD=3.11)	1,30 (SD=1.081)	3,40 (SD=1.635)	17.95 (SD=13.113)	10.65 (SD=10.075)	44.2 (SD=23.187)	11.85 (SD=7.91)	387.00 (SD=82.007)	363.47 (SD=109.598)

Time 2

	SCQ2	ADOS-Com2	ADOS-Soc2	ADOS-Imag2	ADOS-Ster2	C&FD2	FS2	BPVS2	Raven2	CDI-U2	CDI-U/S2
GREECE	11.45 (SD=5.176)	3.95 (SD=2.089)	4.80 (SD=2.949)	1.20 (SD=1.105)	2.90 (SD=1.619)	22.70 (SD=13.849)	12.45 (SD=10.272)	51.40 (SD=23.372)	13.80 (SD=8.205)	387.30 (SD=88.679)	368.85 (SD=103.7233)
UK	11.22 (SD=5.806)	4.50 (SD=2.684)	5.61 (SD=2.95)	1.17 (SD=0.857)	2.22 (SD=1.629)	19.89 (SD=14.919)	12.72 (SD=14.580)	52.00 (SD=26.366)	16.17 (SD=11.057)	416.00 (SD=.00)	390.39 (SD=68.982)

Figure 3. ADOS-Social scores for groups over time

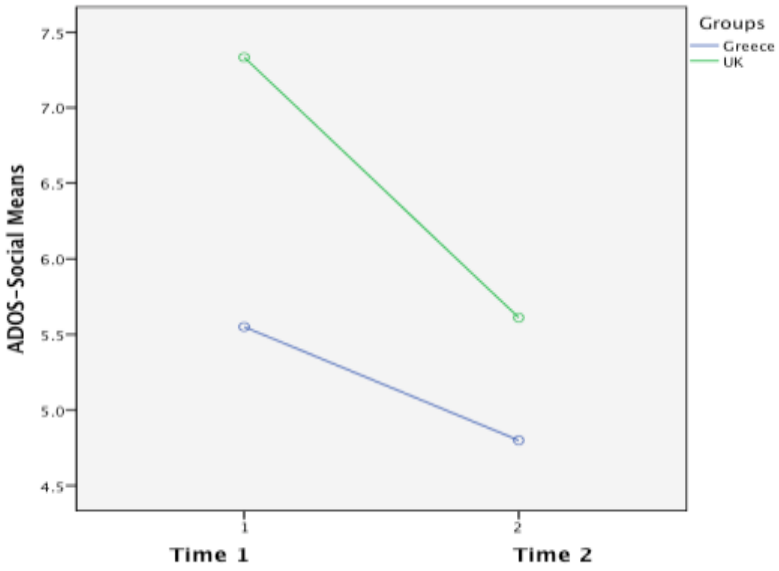


Figure 4. ADOS-Imagination scores for groups over time

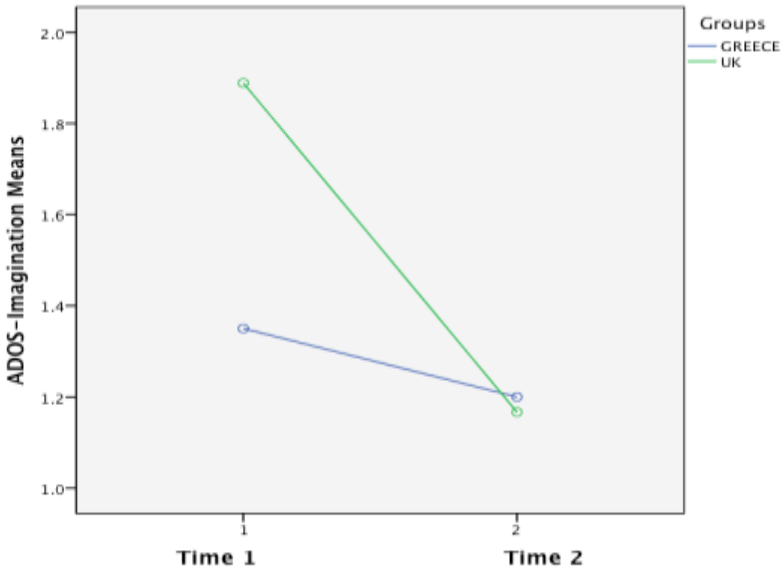


Figure 5. CDI-U scores for groups over time

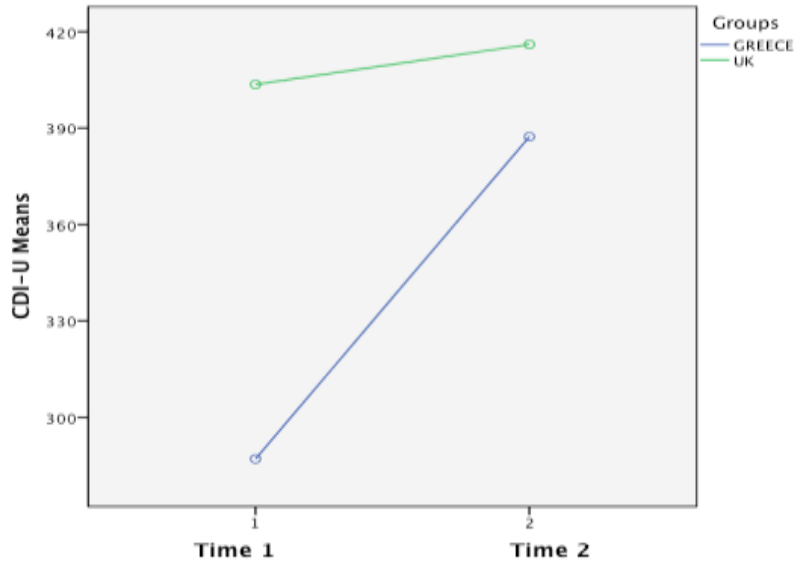


Figure 6. CDI-U/S scores for groups over time

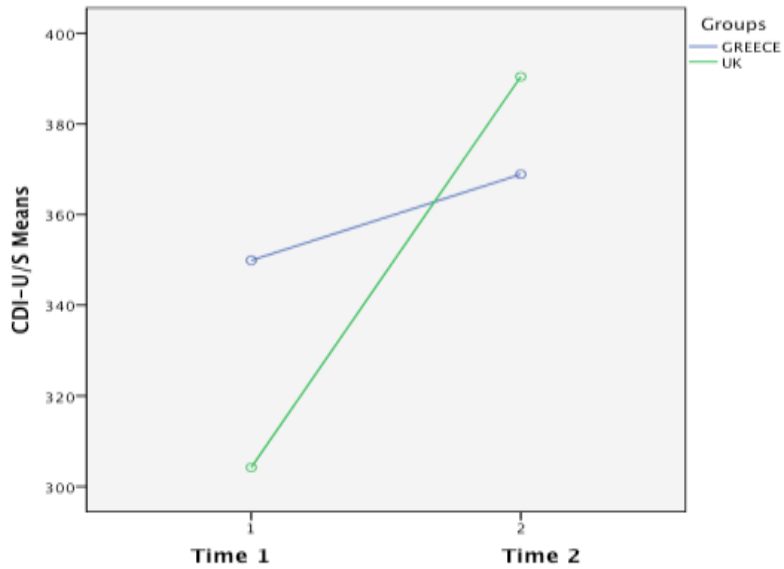


Table 27. Comparison of the progress of the children in the different resident countries-statistical details

Measure	Time	Group	Interaction
Social Communication Questionnaire	F(1,36)=11.126,p=0.002	F(1,36)=0.092,p=0.763	F(1,36)=3.124,p=0.086
ADOS - Communication	F(1,36)=30.276,p<0.001	F(1,36)=1.507,p=0.228	F(1,36)=3.976,p=0.054
ADOS - Social	F(1,36)=45.953,p<0.001	F(1,36)=1.631,p=0.210	F(1,36)=7.107,p=0.011, η2p=0.165
ADOS - Imagination	F(1,36)=18.322,p<0.001	F(1,36)=0.582,p=0.451	F(1,36)=7.886,p=0.008, η2p=0.180
ADOS- Stereotypical behaviour	F(1,36)=20.553,p=p<0.001	F(1,36)=0.929,p=0.342	F(1,36)=1.285,p=0.265
Concepts and Following Directions (CELF)	F(1,36)=74.742,p< 0.001	F(1,36)=0.327,p=0.571	F(1,36)=0.190,p=0.665
Formulated Sentences (CELF)	F(1,36)=10.238,p=0.003	F(1,36)=0.000,p=0.998	F(1,36)=0.210,p=0.650
British Picture Vocabulary Scale II	F(1,36)=75.657,p< 0.001	F(1,36)=0.133,p=0.720	F(1,36)=0.821,p=0.378
Raven's Coloured Progressive Matrices	F(1,36)=21.173,p<0.001	F(1,36)=0.460,p=0.502	F(1,36)=0.236,p=0.630
MacArthur CDI – no of words understood	F(1,36)= 8.698,p=0.006	F(1,36)=7.620,p=0.009	F(1,36)=5.280,p=0.027, η2p=0.138
MacArthur CDI – no of words understood &produced	F(1,36)=15.994, p<0.001	F(1,36)=0.120,p=0.731	F(1,36)=6.540,p=0.015, η2p=0.154

8.3 Development of Greek children and English children receiving SLT

In this analysis, the progress of the children (n=18) with the same intervention context (SLT) but different resident countries (Greece, n=10 and the UK, n=8) was compared over time. Mixed 2 (group) x 2 (time) ANOVAs were completed on the various outcome measures. Most measures showed change over time, except SCQ, ADOS-Ster and CDI-U. Overall it can be seen that children with autism who received SLT are developing in a very similar way across the two countries. Only the ADOS-Social (Figure 7) and the Social Communication Questionnaire (SCQ) (Figure 8) showed a significant interaction effect (see table 28 below). Thus, the SLT group from the UK seem to improve faster in the area of social skills compared to the SLT group from Greece. Furthermore, there was a main effect of group for ADOS-Communication scale and for the ADOS – imagination scale. The children from the SLT group from Greece had lower scores in both assessment measures. In Table 28 the statistical details are provided and the η2p values reflected a large effect.

Figure 7. ADOS-Social scores for groups over time

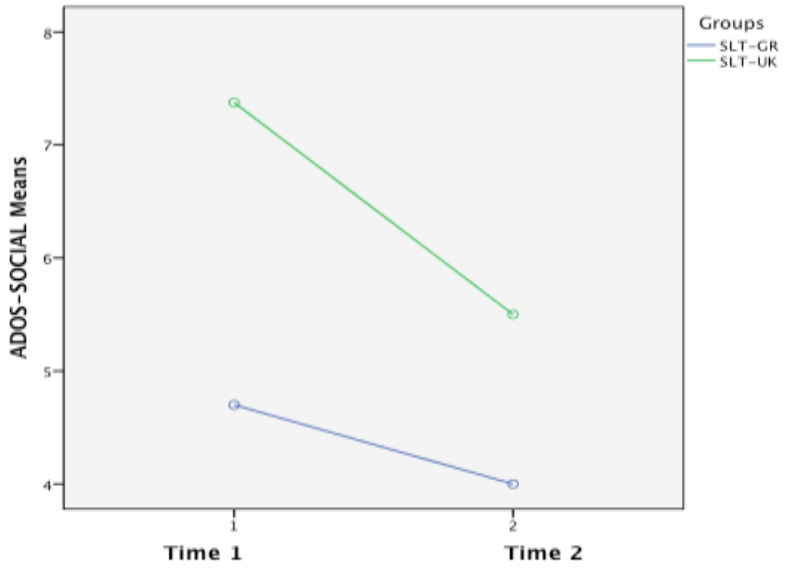


Figure 8. SCQ scores for groups over time

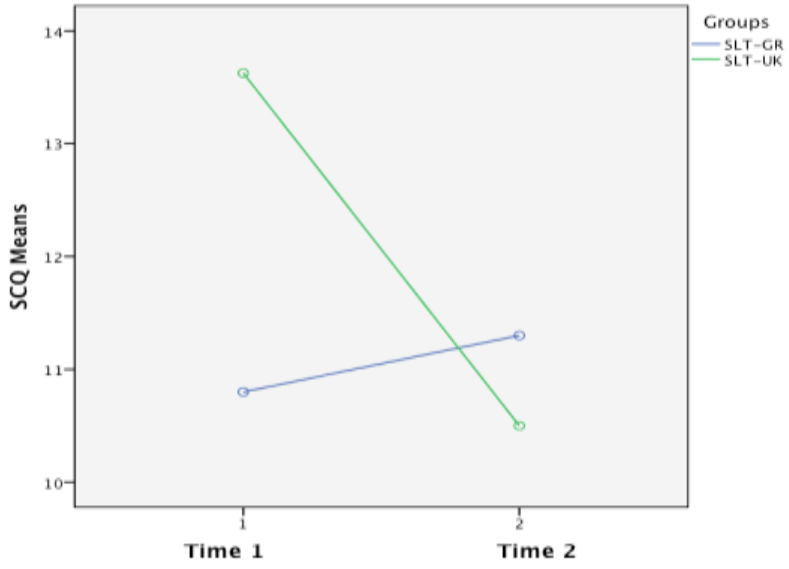


Table 28. Development of Greek children and English children receiving SLT

Measure	Time	Group	Interaction
Social Communication Questionnaire	F(1,16)=3.466,p=0.081	F(1,16)=0.318,p=0.581	F(1,16)=6.610,p=0.021, η2p=0.292
ADOS - Communication	F(1,16)=21.915,p<0.001	F(1,16)=6.222,p=0.024	F(1,16)=3.042,p=0.100
ADOS - Social	F(1,16)=31.487,p<0.001	F(1,16)=2.917,p=0.107	F(1,16)=6.556,p=0.021, η2p=0.291
ADOS - Imagination	F(1,16)=6.222,p=0.024	F(1,16)=6.472,p=0.022	F(1,16)=1.143,p=0.301
ADOS-Stereotypical behaviour	F(1,16)=4.506,p=0.050	F(1,16)=0.689,p=0.419	F(1,16)=0.282,p=0.603
Concepts and Following Directions (CELF)	F(1,16)=41.873,p<0.001	F(1,16)=0.660,p=0.429	F(1,16)=0.236,p=p=0.634
Formulated Sentences (CELF)	F(1,16)=9.665,p=0.007	F(1,16)=0.873,p=0.364	F(1,16)=1,612,p=0.222
British Picture Vocabulary Scale II	F(1,16)=47.544,p<0.001	F(1,16)=0.133,p=0.720	F(1,16)=0.821,p=0.378
Raven's Coloured Progressive Matrices	F(1,16)=16.467,p=0.001	F(1,16)=0.722,p=0.408	F(1,16)=2.033,p=0.173
MacArthur CDI – no of words understood	F(1,16)= 2.399,p=0.141	F(1,16)=2.399,p=0.141	F(1,16)= 2.399,p=0.141
MacArthur CDI – no of words produced	F(1,16)=6.569,p=0.021	F(1,16)=0.524,p=0.480	F(1,16)=3.100,p=0.097

8.4 The effect of country and intervention context on development over time

In this section, a series of 4 x 2 ANOVAs were performed to identify whether country and intervention context affected change over time. See Table 29 for means and SDs. The 4 groups were those identified in methods - SLT in UK; Psychotherapy in UK; SLT in Greece; and OT in Greece. All measures showed change over time and only the CDI-no of words understood (CDI-U) showed a main effect of group. As it can be seen in table 29 most of the participants reached ceiling in the CDI assessment. Namely, the means (SDs) for CDI-U SLT group from Greece time 2 and SLT group from UK time 1 and 2 and Psychotherapy group time 2 are all 416 (SD=0). The CDI is usually used with younger

children but because of the wide age range of the participants in the present study a checklist that covers the vocabulary of all children was needed. Also, the specific tool is widely used, it has been translated in many languages and has been used cross-nationally, because it contains single words and it is wide in context. Moreover, it can be seen that even in the older children still there was change over time which shows that there was development in this area as well. Overall it can be seen that children with autism are developing in a very similar way across countries. Furthermore, only the SCQ (Figure 9) and the ADOS-imagination (Figure 10) showed a significant interaction effect (see details in table 30) before adjusting for age. The SLT group in the UK seems to improve faster in the social communication area and the figures suggest that the Psychotherapy group in the UK improved faster in the area of imagination. Also, the η2p values in table 30 demonstrated moderate effect sizes. Analyses were also repeated using age as a covariate (see details in table 31). It was found then that for four of the assessments, the ADOS-Social, the Concepts and Following Directions (CELF), the Formulated Sentences (CELF) and the Raven's Coloured Progressive Matrices the change over time stopped being significant when age at recruitment was considered suggesting that for these skills the age of the child makes a difference to rate of development. On the other hand, interaction with therapy context became significant for two of the assessment measures, the ADOS-Communication and the MacArthur CDI-no of words produced. Figures 11 and 12 suggest that the OT group in Greece showed the slowest improvement in the area of communication, language comprehension and production compared to the other groups.

Table 29. All groups- descriptive details

Greece - Time 1

	SCQ1	ADOS-Com1	ADOS-Soc1	ADOS-Imag1	ADOS-Ster1	C&FD1	FS1	BPVS1	Raven1	CDI-U1	CDI-U/S1
SLT	10.8 (SD=3.39)	4 (SD=1.33)	4,7 (SD=2.21)	1,2 (SD=.63)	3,1 (SD=1.20)	20,90 (SD=12.85)	12,30 (SD=9.58)	44.80 (SD=20.33)	10,80 (SD=6.30)	412,20 (SD=8.13)	374,70 (SD=101 .30)
OT	13.5 (SD=7.40)	5.20 (SD=2.04)	6,40 (SD=3.89)	1,50 (SD=1.35)	3,70 (SD=1.90)	12,70 (SD=8.69)	7.40 (SD=7.76)	37 (SD=23.92)	9.70 (SD=9.27)	362.50 (SD=109.6)	325.10 (SD=142. 03)

Greece - Time 2

	SCQ2	ADOS-Com2	ADOS-Soc2	ADOS-Imag2	ADOS-Ster2	C&FD2	FS2	BPVS2	Raven2	CDI-U2	CDI-U/S2
SLT	11.30 (SD=4.16)	3.20 (SD=.789)	4.00 (SD=1.94)	1.00 (SD=.667)	2.80 (SD=1.22)	26.60 (SD=14.60)	14.40 (SD=10.42)	56.70 (SD=19.48)	13,80 (SD=6.12)	416.00 (SD=.000)	391.40 (SD=61.63)
OT	11.60(SD=6.25)	4.70 (SD=2.71)	5.60 (SD=3.62)	1,40 (SD=1.43)	3.00 (SD=2.00)	18.80 (SD=12.56)	10.50 (SD=10.27)	46.10 (SD=26.66)	13.80 (SD=10.22)	358.60 (SD=121.53)	346.30 (SD=133.35)

UK – Time 1

	SCQ1	ADOS-Com1	ADOS-Soc1	ADOS-Imag1	ADOS-Ster1	C&FD1	FS1	BPVS1	Raven1	CDI-U1	CDI U/S1
PSYCH	13.40 (SD=8.05)	5.90 (SD=3.573)	7.30 (SD=3.945)	1.60 (SD=1.265)	3.40 (SD=1.955)	13.50 (SD=18.241)	10.20 (SD=15.361)	41.00 (SD=30.166)	11.70 (SD=11.33)	393.60 (SD=39.48	301.80 (SD=150.103)
SLT	13.63 (SD=4.897)	5.88 (SD=1.885)	7.38 (SD=3.335)	2.25 (SD=1.165)	2.63 (SD=1.996)	15.88 (SD=9.717)	6.50 (SD=8.944)	39.50 (SD=22.860)	11.88 (SD=8.167)	416.00 (SD=0.00)	307.25 (SD=157.197)

UK - Time 2

	SCQ2	ADOS-Com2	ADOS-Soc2	ADOS-Imag2	ADOS-Ster2	C&FD2	FS2	BPVS2	Raven2	CDI-U2	CDI-U/S2
PSYCH	11.80 (SD=7.177)	4.80 (SD=35.21)	5.70 (SD=3.057)	0.70 (SD=0.675)	2.30 (SD=1.703)	17.80 (SD=18.665)	13.70 (SD=17.282)	49.60 (SD=31.281)	14.60 (SD=13.184)	416.00 (SD=0.00)	384.90 (SD=82.009)
SLT	10.50 (SD=3.817)	4.13 (SD=1.126)	5.50 (SD=3.024)	1.75 (SD=0.707)	2.13 (SD=1.642)	22.50 (SD=8.864)	11.50 (SD=11.364)	55.00 (SD=20.291)	18.13 (SD=8.097)	416.00 (SD=0.00)	397.25 (SD=53.033)

Figure 9. SCQ scores for groups over time

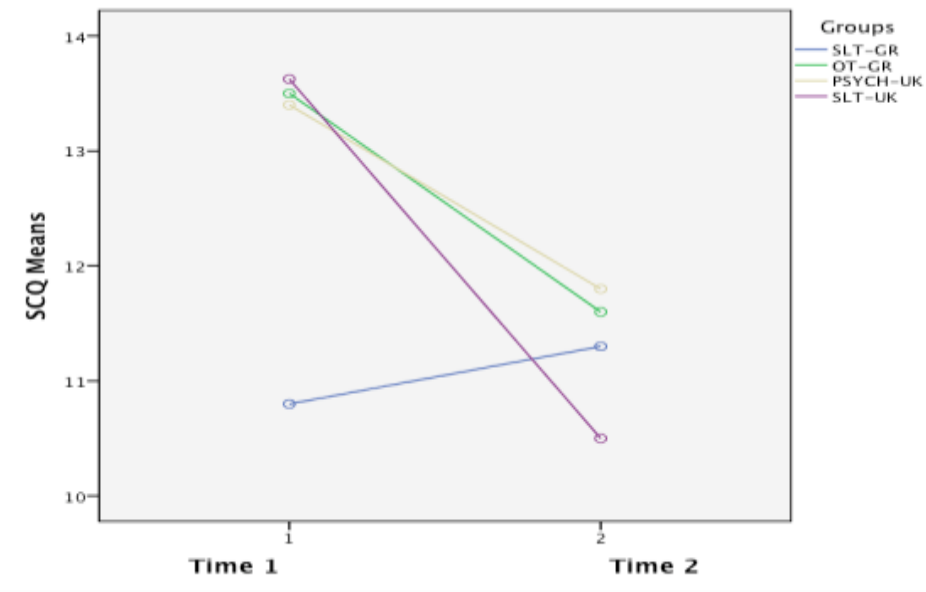


Figure 10. ADOS-Imagination scores for groups over time

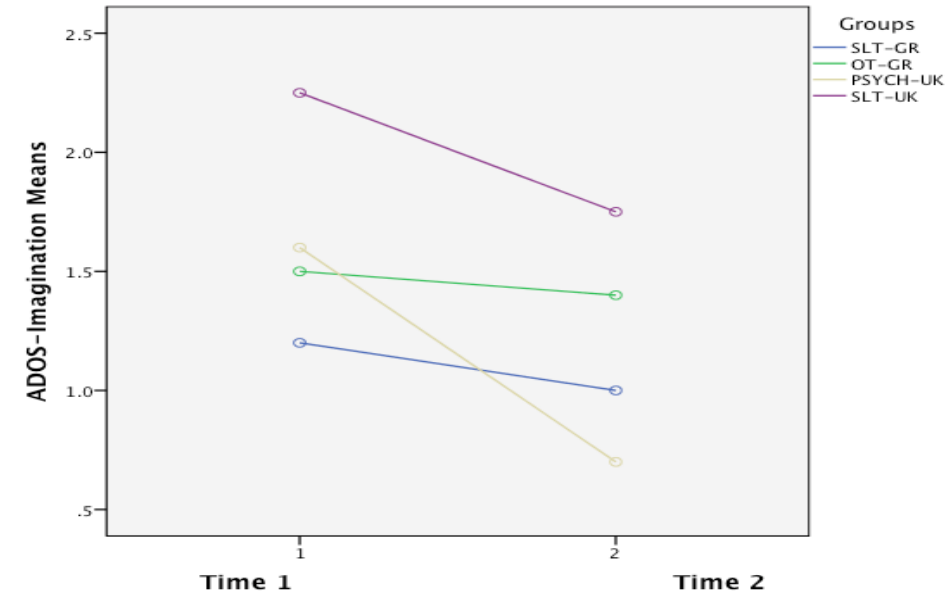


Table 30

All therapy groups over time before adjusting for age

Measure	Time	Group	Interaction
Social Communication Questionnaire	F(1.34)=12.899,p=0.001	F(1.34)=0.153,p=0.927	F(1,34)=3.055,p=0.041, η2p=0.212
ADOS - Communication	F(1,34)=30.962,p<0.001	F(1,34)=1.102,p=0.362	F(1,34)=1.910,p=0.147
ADOS - Social	F(1,34)=44.026,p<0.001	F(1,34|)=0.991,p=0.409	F(1,34)=2.354,p=0.089
ADOS - Imagination	F(1,34)=17.254,p<0.001	F(1.34)=1.492,p=0.234	F(1,34)=3.267,p=0.033, η2p=0.224
ADOS- Stereotypical behaviour	F(1,34)=19.956,p<0.001	F(1,34)=1.444,p=0.247	F(1,34)=0.515,p=0.675
Concepts and Following Directions (CELF)	F(1.34)=74.984,p<0.001	F(1,34)=0.786,p=0.510	F(1,34)=0.573,p=0.637
Formulated Sentences (CELF)	F(1,34)= 9.942,p=0.003	F(1,34)=0.355,p=0.786	F(1,34)=0.287,p=0.834
British Picture Vocabulary Scale II	F(1,34)=82.843,p<0.001	F(1,34)=0.242,p=0.867	F(1,34)=1.522,p=0.227
Raven's Coloured Progressive Matrices	F(1,34)=22.021,p<0.001	F(1,34)=0.214,p=0.886	F(1,34)=0.740,p=0.536
MacArthur CDI – no of words understood	F(1,34)=8.072,p=0.008	F(1,34)=4.048,p=0.015	F(1,34)=1.810,p=0.164
MacArthur CDI – no of words produced	F(1,34)=15.137,p<0.001	F(1,34)=0.364,p=0.780	F(1,34)=2.077,p=0.122

Table 31

All therapy groups over time after adjusting for age (the results that changed are marked in red)

Measure	Time	Group	Interaction
Social Communication Questionnaire	F(1.34)=12.899,p=0.01	F(1.34)= 0.153,p=0.927	F(1,34)= 3.055,p=0.041
ADOS - Communication	F(1,34)=30.962,p<0.001	F(1,34)=1.102,p=0.362	F(3,33)= 3.400,p=0.029
ADOS - Social	F(1,33)= 3.641, p= 0.065	F(1,34)=0.991,p=0.409	F(1,34)= 2.354,p=0.089
ADOS - Imagination	F(1,34)= 17.254,p<0.001	F(1.34)= 1.492,p=0.234	F(1,34)= 3.267,p=0.033
ADOS-Stereotypical behaviour	F(1,34)= 19.956,p<0.001	F(1,34)= 1.444,p=0.247	F(1,34)=0.515,p=0.675
Concepts and Following Directions (CELF)	F(1,33)= 3.957, p= 0.055	F(1,34)=0.786,p=0.510	F(1,34)=0.573,p=0.637
Formulated Sentences (CELF)	F(1,33)= 0.240, p=0.627	F(1,34)=0.355,p=0.786	F(1,34)=0.287,p=0.834
British Picture Vocabulary Scale II	F(1,34)=82.843,p< 0.001	F(1,34)=0.242,p=0.867	F(1,34)=1.522,p=0.227
Raven's Coloured Progressive Matrices	F(1,33)= 1.444, p=0.238	F(1,34)=0.214,p=0.886	F(1,34)=0.740,p=0.536
MacArthur CDI-no of words understood	F(1,34)=8.072,p=0.008	F(1,34)=4.048,p=0.015	F(1,34)=1.810,p=0.164
MacArthur CDI-no of words produced	F(1,34)= 15.137,p<0.001	F(1,34)=0.364,p=0.780	F(3,33)=3.897,p=0.017

Figure 11. ADOS-Communication scores for groups over time after adjusting for age

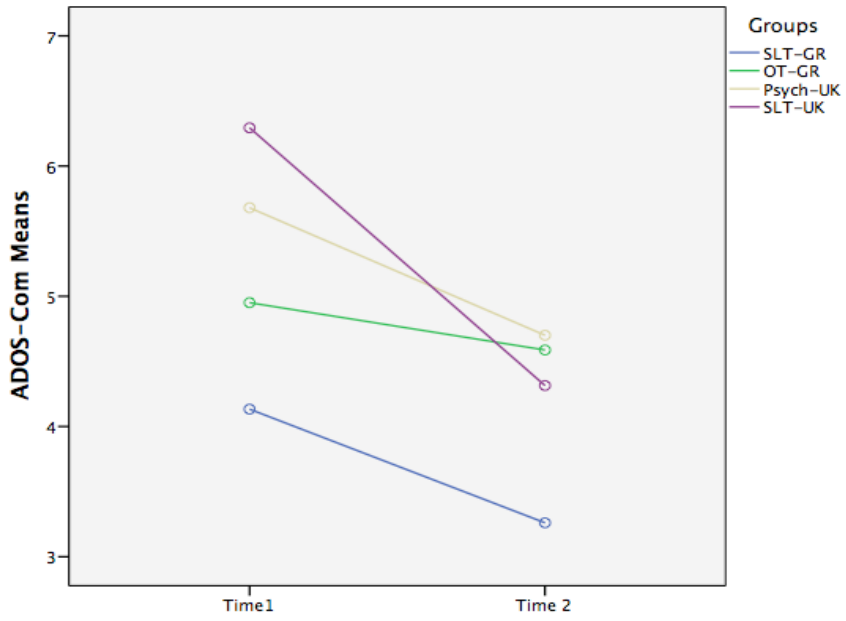
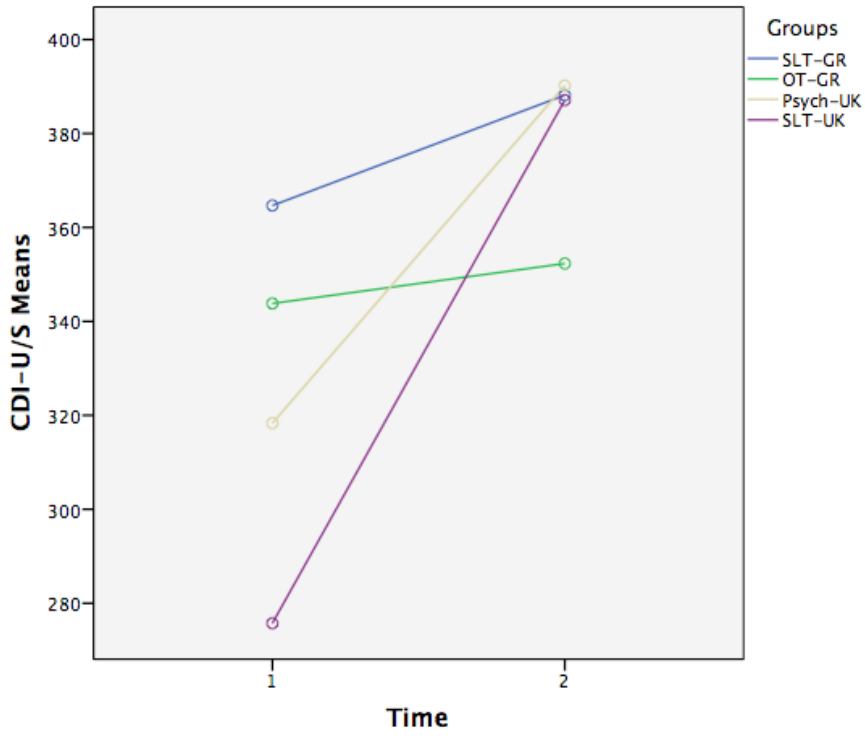


Figure 12. CDI-U/S scores for groups over time after adjusting for age



8.5. Development of children experiencing different intervention contexts – within countries

In this analysis, the data were explored in a different way. This time children residing within the same country were compared across different intervention backgrounds.

i) Greece: The progress of the different therapy groups in Greece was compared over time. Mixed 2 (group) x 2 (time) ANOVAs were completed on the various outcome measures. The overall pattern of these revealed few effects – the children changed significantly over time on all aspects of measurement, except for the SCQ, ADOS-Communication and ADOS-Imagination but there were no group differences nor significant interactions suggesting that there is developmental change, but little added effect of one particular therapy context over the other. See table 32 for the statistical details. See table 29 for means and SDs.

Table 32. Differences between therapy groups over time-Greece

Measure	Time	Group	Interaction
Social Communication Questionnaire	F(1,18)=1.2, p=0.29	F(1,18)=0.39, p=0.54	F(1,18)=3.6, p=0.075
ADOS - Communication	F(1,18)=7.5, p= 0.13	F(1,18)=2.84, p=0.109	F(1,18)=0.403,p=0.534
ADOS - Social	F(1,18)=14.78,p=0.01	F(1,18)=1.503,p=0.236	F(1,18)=0.066,p=0.081
ADOS - Imagination	F(1,18)=3.24,p=0.089	F(1,18)=0.535,p=0.474	F(1,18)=0.360,p=0.556
ADOS- Stereotypical behaviour	F(1,18)=7.37,p=0.014	F(1,18)=0.325,p=0.575	F(1,18)=1.18, p=0.292
Concepts and Following Directions (CELF)	F(1,18)=32.72,p<0.001	F(1,18)=2.16,p= 0.158	F(1,18)=0.038,p=0.848

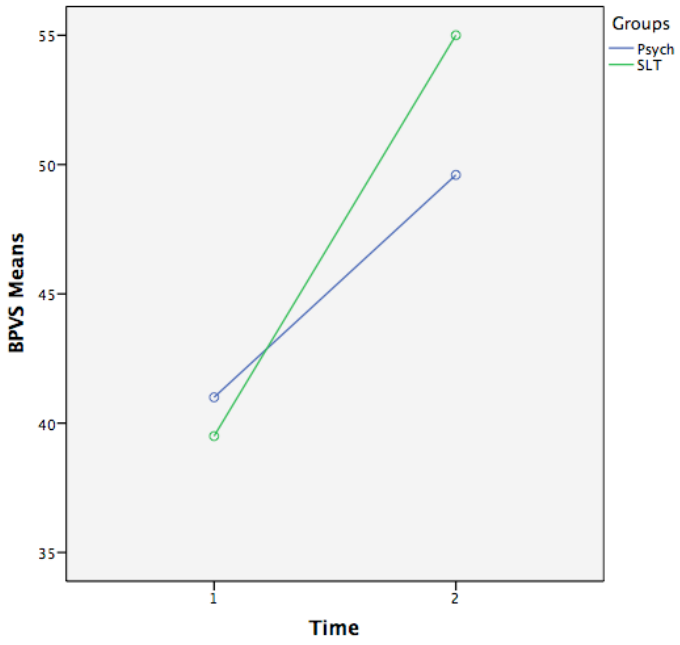
Formulated Sentences (CELF)	F(1,18)=9.98,p=0.005	F(1,18)=1.097,p=0.309	F(1,18)=0.369,p=0.551
British Picture Vocabulary Scale II	F(1,18)=27.64,p<0.001	F(1,18)=0.848,p=0.369	F(1,18)=0.491,p=0.492
Raven's Coloured Progressive Matrices	F(1,18)=8.71,p=0.009	F(1,18)=0.025,p=0.875	F(1,18)=0.209,p=0.653
MacArthur CDI – no of words understood	F(1,18)=7.56, p= 0.013	F(1,18|)=2.150,p=0.160	F(1,18)=0.126,p=0.727
MacArthur CDI - no of words produced	F(1,18)=5.58,p=0.030	F(1,18)=0.884,p=0.360	F(1,18)=0.079,p=0.782

ii) UK: In this analysis, the progress of the different therapy groups in the UK was compared over time. Mixed 2 (group) x 2 (time) ANOVAs were completed on the various outcome measures. Similarly to the Greek data, the overall pattern of these revealed few effects –the children changed significantly over time on all aspects of measurement except for the Formulated Sentences (CELF) and the CDI-no of words understood but there were no group differences. Additionally the BPVS showed a significant interaction effect, suggesting that in the SLT group there was a higher increase of the children's receptive vocabulary (figure 13) and a large effect size was determined ($\eta 2p=0.286$). See table 33 for the statistical details.

Table 33. Differences between therapy groups over time-UK

Measure	Time	Group	Interaction
Social Communication Questionnaire	F(1,16)=18.191,p=0.001	F(1,16)=0.032,p=0.860	F(1,16)=1.895,p=0.188
ADOS - Communication	F(1,16)=23.672,p<0.001	F(1,16)=0.070,p=0.794	F(1,16)=1.231,p=0.284
ADOS - Social	F(1,16)=27.457,p<0.001	F(1,16)=0.002,p=0.969	F(1,16)=0.172,p=0.684
ADOS - Imagination	F(1,16)=12.787,p=0.003	F(1,16)=3.945,p=0.064	F(1,16)=1.044,p=0.322
ADOS- Stereotypical behaviour	F(1,16)=12.218,p=0.003	F(1,16)=0.322,p=0.579	F(1,16)=1.718,p=0.208
Concepts and Following Directions (CELF)	F(1,16)=50.528,p<0.001	F(1,16)=0.245,p=0.627	F(1,16)=2.288,p=0.150
Formulated Sentences (CELF)	F(1,16)=4.057,p=0.061	F(1,16)=0.219,p=0.646	F(1,16)=0.126,p=0.727
British Picture Vocabulary Scale II	F(1,16)=78.164,p<0.001	F(1,16)=0.023,p=0.881	F(1,16)=6.407,p=0.022, η2p=0.286
Raven's Coloured Progressive Matrices	F(1,16)=13.580,p=0.002	F(1,16)=0.142,p=0.712	F(1,16)=1.820,p=0.196
MacArthur CDI – no of words understood	F(1,16)=2.546, p= 0.130	F(1,16)=2.546,p=0.130	F(1,16)=2.546,p=0.130
MacArthur CDI – no of words produced	F(1,16)=10.044,p=0.006	F(1,16)=0.032,p=0.860	F(1,16)=0.016,p=0.901

Figure 13. BPVS scores for UK groups over time



8.6 Summary of results

In summary, it was found that all children changed significantly over time on all aspects of measurement, regardless of country or intervention context. Also, the progress of the different speech and language therapy groups in Greece and the UK was compared over time and it was found that children with autism are developing in a very similar way across the two countries, even when intervention context was held constant. Nonetheless, based on the results the SLT groups showed more change on language and communication measures, whilst the psychotherapy group saw changes in other areas of autistic symptomatology not achieved in the SLT group, such as stereotypical behaviour and imagination. The possible reasons for these differences in change over time will be discussed later.

When the progress of the children in the different resident countries was compared over time it was demonstrated that the children changed significantly over time on all aspects of measurement. However, the children in the UK improved faster

in the areas of social skill and imagination and there was a higher increase in their ability to understand and say words compared to the children in Greece. The children from Greece on the other hand improved faster in the area of comprehension but it is worth mentioning that the scores of the children from the UK might have already reached ceiling in that assessment (CDI-U).

In regards to the progress of the children with the same intervention context (SLT) but different resident countries, it was seen that children changed significantly over time in most of the assessments except for the SCQ, ADOS-Ster and CDI-U. Therefore, since it was previously seen that there was a significant change over time on all aspects of measurement when the progress of the children in the different resident countries was compared over time, it can be noted that the other two types of therapy (OT and psychotherapy) might have contributed to the significant change of these measures. Also, the SLT group from the UK seems to improve faster in the area of social skills compared to the SLT group from Greece. Furthermore, the children from the SLT group from Greece had lower scores in the ADOS-Communication scale and ADOS – imagination scale.

When exploring whether country and intervention context affected change over time it was determined that all measures showed change over time and that children with autism are developing in a very similar way across countries. However, the SLT group in the UK seems to improve faster in the social communication area and the Psychotherapy group in the UK improved faster in the area of imagination.

Overall, with respect to the speech and language therapy group in Greece the ADOS results demonstrated the children's improvements in the realms of social interaction, the CELF results showed a significant difference in the children's ability to interpret, recall, execute commands and in their ability to formulate compound and

complex sentences and the BPVS showed an increase of their receptive vocabulary. Based on the Raven's Matrices their reasoning ability was also improved after one year, however stereotypical behaviour, imagination through play and social communication did not seem to change. In the occupational therapy group in Greece the ADOS results indicated improvement in the children's social skills over time and the CELF results showed that the children's ability to formulate compound and complex sentences along with their ability to interpret, recall, execute commands advanced in a year. The BPVS showed an increase of their receptive vocabulary and based on the ADOS there was indication that the stereotypical behaviours of the children in this group were reduced over the year. Also, the CDI showed an increase in the words that the children understood and produced.

Some subtle effects of intervention context were noted: In the speech and language therapy group in the UK the ADOS along with the CELF, BPVS and Raven's results showed an overall improvement in the communication and social interaction areas, as well as in reasoning ability. This suggests a wide ranging developmental pattern although again stereotypical behaviour was not improved in this group. In the psychotherapy group in the UK the ADOS results demonstrated that the children in this group used more their imagination during play after one year and the stereotypical behaviours of these children were reduced over the year. In addition, the CELF results showed a significant difference in the children's ability to interpret, recall and execute commands. The CDI showed an increase in the words that the children were able to understand and say and the BPVS showed an increase of their receptive vocabulary but in the SLT group the improvement in this area was higher.

In summary, whilst the country appeared to make little difference to changes over time, the intervention context may have subtle effects on the aspects of autism,

which change over time. Namely children who have received non-speech and language based therapies appear to make more progress on stereotypical behaviour and cognitive flexibility despite being at a similar level at the start of this study. However, the number of comparisons and small sample size mean that the results need to be interpreted with some caution and this will be discussed further in chapter nine.

Chapter 9 Discussion

The purpose of this study was to investigate whether children with autism show significant development in the areas of social skill and communication, regardless of the kind of treatment they are receiving and to explore the association between therapy context and the patterns of developmental change. In this chapter the aspects of the disorder that differ in the UK and Greece will be evaluated along with the differences (if any) in the developmental patterns across countries.

9.1 Main Findings

In this research study, all children changed significantly over time on all aspects of measurement. Based on the assessments of the children living in Greece and the UK, children with autism are developing in a very similar way across the two countries. No differences were found at the start of the study, or in the rates of change in skills. With respect to the effect of the therapy context on the development of children with autism, it was found that there were no differences across intervention contexts at the start of the study and there were mainly non-significant interactions in the rate of change across the differing types of intervention (to be discussed in greater detail later). However, further analysis showed some important differences, which will be discussed more fully later. Namely, speech and language therapy participants presented more widespread change on language scores across the measures; psychotherapy participants showed significant greater increase in imagination; and occupational therapy participants presented significant reduction of stereotypical behaviour. Finally, it was found that all groups showed improvements in the realms of communication.

9.2 Development of children with autism over time

The children assessed showed progress in their communication and social skills after receiving therapy, regardless of the type of intervention they had received. These results lead us to believe that regardless of the type of therapy that the children received, their skills advanced during the 12 months that they were followed up. In light of the findings from the current study and those of previous studies (Seltzer et al, 2004; McGovern & Sigman, 2005; Sutera et al, 2007; Kelley et al, 2010; Charman et al, 2005), it seems that autism symptoms do change over time. As discussed in chapter one, there is a wide variety of interventions offered to children with autism, which are associated with positive results (Baker-Ericzen et al. 2007; Smith et al, 2010; Francke & Geist, 2003; Kasari et al, 2006; Case-Smith & Bryan, 1999; Linderman & Stewart, 1999; Watling & Dietz, 2007). The positive outcomes of each intervention though might be attributed to the "generalised therapeutic attention" that each family received and this might explain why all children in the present study progressed and that the therapy context did not seem to affect targeted change. In addition, it should be noted that all types of intervention included the use of verbal mediation and that even the one to one interaction that the children had with a therapist might have boosted communication disregarding the type of treatment followed.

It could be that age may contribute to the development of the communication and social skills of the children involved in this study. When age was considered at recruitment the analysis revealed that for the ADOS-Social, the Concepts and Following Directions (CELF), the Formulated Sentences (CELF) and the Raven's Coloured Progressive Matrices the change over time stopped being significant. Thus, the change in children's ability to interpret, recall, reason and execute commands

along with their social skills was affected by age and was no longer significant. On the other hand, the interaction between change and therapy context became significant for two of the measurements that assessed the children's communication skills. Nevertheless, even with some measures designed towards younger children, change was detected over time in all children. With regard to the age that children start treatment, further research is clearly needed. For example, findings from a study by Makrygianni & Reed (2010) in Greece indicated that children's age was only associated with the changes in autistic severity; the younger a child was at baseline, the greater the decrease in their autistic severity.

The findings of this study suggest that regardless the type of therapy that parents choose for their children, there can be improvement in their development. Research has suggested that parental stress is strongly correlated with the child's level of negative behaviour (Estes et al, 2009). Parents of children with autism spectrum disorders experience increased challenges because of the nature of the disorder. For example, research by Maljaars et al, (2013) suggests that parenting a child with autism requires a great deal more activity compared to parenting a typically developing child. Thus, parents of children with autism often need to adapt the environment depending on their child's needs. Additionally, Maljaars et al (2013) reported that parents of children with autism focus more on good behaviours and less on the repercussions of negative behaviours. Higher levels of stress in parents of children with autism have been identified throughout the literature (Kasari & Sigman, 1997; Rutgers et al, 2007; Baker-Ericzen et al, 2005; Abbeduto et al, 2004) compared to parents of typically developing children and parents of children with other developmental disabilities. Also, the fact that there are always new treatments on offer may make them feel that they are not doing enough (Solomon & Chung, 2012).

When a child receives therapy the whole family may start to feel supported and less isolated so this shift in the family dynamics might also contribute to a child's progress. Indeed this was a finding in a study by Siklos & Kerns (2006) that parents of children with autism are in need of consistent therapy with their children as well as assistance from knowledgeable professionals and that the ones who receive support show healthier adaptation to having a child with autism. Kourkoutas et al, (2012) confirms that families are more likely to better develop their own resources when they are advised and supported in a positive way. In a study by Bristol (1984) parents stated that their most important coping mechanism was the notion that their child's services had the family's best interest in mind. This suggests that the belief that their child is receiving the appropriate services is important for parents in order to cope with the diagnosis.

9.3 Effect of country on the development of children with autism

In this study it can be seen that no significant differences were found in children with autism across Greece and the UK at the start of the study and only a few differences were demonstrated in their patterns of development over time. Namely, when the progress of the children between the different resident countries was compared over time, it was demonstrated that all children changed significantly but the children from the UK showed a faster improvement in the ADOS-social, ADOS-imagination and CDI-U/S and the Greek children demonstrated higher scores in the CDI-U. Overall, the children in the UK seem to have improved faster in the areas of social skill, imagination and in their ability to understand and say words compared to the children in Greece. On the other hand there was a faster improvement of the children from Greece in the area of comprehension based solely on the CDI-U.

Nonetheless, the children from the UK already had very high scores in this measurement, thus they could have already showed ceiling performance on this assessement tool.

When the progress of the children with the same intervention context (SLT) but different resident countries was compared, it was noted that all measures showed significant change except for the SCQ, ADOS-Stereotypical and CDI-U. Therefore, the differences found in these measures in the overall sample might have been driven by the other therapy groups (psychotherapy and occupational therapy). Considering the results of the comparison of therapies within countries (section 8.5) as well, it can be determined that the change in the SCQ is driven by the psychotherapy group because in the Greek sample there was no significant change in this measure over time. Additionally, it was demonstrated that the UK children had higher scores in the ADOS-communication and ADOS-imagination and that they improved faster in the ADOS-social and SCQ. As it was mentioned in section 7.4, the SLT service in the UK seems to offer a wider range of techniques and strategies with respect to children's social/behavioural skills compared to the one in Greece. To that end, it could be explained why the children that had SLT in the UK improved more in the areas mentioned above.

The fact that in the majority the children are similar between the two countries supports the notion of autism being diagnosed in similar ways across countries (Sipes et al, 2011) and suggests cross-cultural validity of the disorder. International diagnostic measures, such as the ADI-R and ADOS, are used across countries to diagnose autism. For example, in the UK and Greece the same diagnostic assessment measures are used (Baird et al., 2006; Papanikolaou et al, 2009). These measures have provided a format for clinicians to follow which makes it easier for them to provide a

standard diagnosis based on the Diagnostic and Statistical Manual of Mental Disorders- fifth edition (DSM-5 R). This set of diagnostic criteria that different countries have in common along with the structured assessment measures guarantee a shared unit of analysis in clinical practice and research around the world (Matson & Sturmey, 2011). In a study by Papageorgiou et al (2007) the authors explored a specific category of autism symptoms (restricted and repetitive behaviours and interests) in Greek children and compared it with previous findings from North America. The results suggested a cross-cultural heterogeneity of the Restricted and Repetitive Behaviours and Interests domain of autism. However, there are some studies (Mandy et al, 2014; Baron-Cohen et al, 2001) suggesting that ASD manifests differently across countries and thus there may be some cultural divergence in the presentation of ASD (Wakabayashi et al, 2006; Freeth et al, 2013). Matson et al (2011) reported higher levels of severity in the autistic symptoms of children with ASD in the UK and US in comparison to those in Israel and South Korea.

Given the wide range of cultures in which the disorder has been reported, one would expect to find a rich and extensive international research literature; instead surprisingly little is known about autism within a cultural context. According to Ennis-Cole et al (2013) the decisions families make about autism diagnosis and treatment are directly influenced by the family's cultural background. Thus it appears that culture may have influenced the way that parents perceive the signs and symptoms of autism. For example, Mandell & Novak (2005) found that English parents are more inclined to pay attention to general developmental delays or regression of language than social difficulties. This could be explained by the fact that the English culture places more importance on language than on social skills and

often parents believe that their children might overcome these social issues on their own.

The salient features of cultures may influence what parents notice first, for example, it was found by Mandell & Novak (2005) that Eastern Indian parents are more likely to see social difficulties in their children before speech problems. Pitten (2008) suggests that this might be linked to the emphasis the Indian culture places on social conformity. Social status in Greece is considered more important compared to the English culture (Argyrakouli and Zafiropoulou, 2003). Research has shown (Argyrakouli and Zafiropoulou, 2003) that in the Greek culture a family might not be fully accepted by the society if they have a disabled child which leads to elevated parental stress. Osborne et al (2008) reported that parental stress has a negative impact on child outcomes receiving intensive intervention for children with autism. Therefore, the negative attitudes towards disability that are more evident in Greece could possibly contribute to higher parental stress, which in turn could influence the development of children with autism. This notion led to the initial assumption that the development of children with autism might differ across the UK and Greece. However, the results did not fully support this hypothesis, since the children showed similarities in most of the areas of development that were assessed. A plausible explanation for the observed similarities in the manifestation of autism between the two countries could be that both the UK and Greece are Western developed societies. Additionally, the fact that the participants were receiving private treatment increases the homogeneity of the population between the two countries.

9.4 Effect of therapy context on the development of children with autism

When the children residing within the same country were compared across

different therapy backgrounds, it was found that the children changed significantly over time on most aspects of measurement but only one significant interaction effect was found suggesting little added effect of one particular therapy context over the other. More specifiacally, when the children residing in the UK were compared across different therapy backgrounds, it was found that the BPVS showed a significant interaction effect, demonstrating that the receptive vocabulary of the UK SLT group increased faster compared to the psychotherapy group.

It is of interest though that the intervention context did not seem to fully associate with rate of change. It might be expected, for example, that the children receiving speech and language therapy would progress more in their communication skills because this is the targeted skill. Several studies have found, for example, that the use of PECS, which is used by speech and language therapists, boosts spoken communication in children with ASD (Charlop Christy et al, 2002; Ganz et al, 2007; Yoder & Stone, 2006). More specifically, Yoder & Stone (2006) found that PECS helped children more in their communication and spoken language. In addition, based on Romski et al (2010), augmented language interventions promoted speech production abilities in young children with developmental difficulties. A more recent study by Lerna et al (2014) focused on the long-term effectiveness of PECS and reported that PECS training helps improve children's social-communicative skills as well.

However, it should be taken into account that in the current study therapists across all intervention types stated that they focus on the development of children's communication skills, as seen in the questionnaires (Appendix III). This could explain why all children progressed in a similar way in the language and communication area, since all services appeared to have common aims; to facilitate communicative

development – a key aspect of impairment in autism. Furthermore, one of the interventions that was often provided to the individuals with ASD while they were receiving another type of intensive treatment was speech and language therapy (Appendix III). Therefore they might have improved in the area of language and communication due to their participation in an SLT program at some point of their treatment.

9.5 Therapy specific changes

Despite this more universal picture of change, further analysis of the data revealed some important context specific features of change. For example, the children from the speech and language therapy group in Greece showed particular improvement in the social area and increased communication skills over time. More specifically, the ADOS results demonstrated the children's improvements in the realms of social interaction. The CELF results showed a significant difference in the children's ability to interpret, recall and execute commands and the BPVS showed an increase of their receptive vocabulary. Reasoning ability was also improved in this group after one year.

In the occupational therapy group in Greece the ADOS demonstrated improvement in the social area over time and the CELF results showed that the children's ability to formulate compound and complex sentences advanced in a year. Similar findings were reported by Hebert et al (2014) who also investigated the role of occupational therapy for the promotion of communication in children with autism and highlighted the importance of occupational therapy in promoting early communication skills. In the current study the BPVS and the CDI showed an increase of the children's receptive vocabulary along with the words that they understood and

produced and based on the ADOS there was some indication that the stereotypic behaviours of the children in this group were reduced over the year. This could be attributed to the attention that occupational therapists pay on decreasing stereotypic behaviours by using various sensory-based treatment techniques (Ayres, 1979). Watling & Dietz (2007) and Linderman & Stewart (1999) also reported progress in social interaction in children receiving occupational therapy and Makrygianni & Reed (2010) found that Greek intervention programmes were quite helpful in improving stereotypic behaviours, which affect autistic severity, and learning procedures. As a result, further studies could shed light to the changes on this autistic feature.

When the progress of the different therapy groups in Greece was compared over time it was found that the children changed significantly on all aspects of measurement except for the SCQ, ADOS-communication and ADOS-imagination. Therefore, the difference in these measures, which was seen in the sample as a whole, was driven by the UK sample.

In the speech and language therapy group from the UK the results showed that the children's social and communication skills advanced over time. Also, the BPVS showed an increase in their receptive vocabulary and the Raven's reflected an increase in their reasoning ability. With regard to the increase in the social-communicative behaviours in both SLT groups the findings are consistent with prior research on the relationship between speech and language therapy and social and communication skills (Yoder & Stone, 2006; Yoder & Lieberman, 2010; Gordon et al, 2011; Charlop-Christy et al, 2002; Ganz & Simpson, 2004 and Sulzer-Azarroff et al, 2009). The children from the Psychotherapy group in the UK showed more imagination during play after one year, fewer stereotypic behaviours and a richer vocabulary. The rest of the assessments showed a significant difference in the

children's ability to interpret, recall and execute commands along with their social communication skills.

When the progress of the children from the different therapy groups in the UK was compared over time, it was determined that the children changed significantly on all aspects of measurement except for the FS and CDI-U, which leads us to believe that the difference in these measures previously found in the whole sample, was driven by the Greek group. Furthermore, the group effect of the ADOS-imagination ($p=0.064$) and the fact that the interaction became significant for the BPVS, suggest that psychotherapy might affect children's imagination in a positive manner and that SLT might have a positive effect on children's receptive vocabulary skills.

It is of particular interest that there was a significant reduction of stereotypic behaviours in the children from the psychotherapy and occupational therapy groups because this kind of behaviour can interfere with several aspects of everyday life. Stereotypic behaviour is included as one of the diagnostic criteria for autism (DSM-5) and it has been defined as "repetitive and apparently purposeless body movements, (e.g. body rocking) body part movements (e.g. hand flapping, head rolling) or use of the body to generate object movements (e.g. plate spinning, string twirling)" (Lewis & Bodfish, 1998; p.82). Therefore, this behaviour can affect the development of various skills and could be socially stigmatizing. If frequent, stereotypies might hinder the ability of children to acquire appropriate play skills and by extension this behaviour could inhibit social interaction with peers as well as family members and interfere with learning (Krantz & McClannahan, 1998; Goldman & Greene, 2013). Reese et al (2003, 2005) conducted indirect assessments with care providers of children with autism in order to explore the relationship between stereotypy and challenging behaviour. Based on the results the authors suggested that children with

autism may be presenting challenging behaviours that are specifically related to the stereotyped behaviours associated with their diagnosis. These results were also supported by White et al (2011) who suggested a relationship between stereotypy and socially mediated challenging behaviour.

The more specific changes that the subgroup analysis revealed fit well with the intervention targets of each type of therapy. As it can be seen in the questionnaires (Appendix I) each intervention focuses on advancing different skills and this was reflected in the results mentioned earlier. However, with respect to the occupational therapy group in Greece and the psychotherapy group in the UK it should be taken into account that the children were on average younger than those in the speech and language therapy groups. This might have influenced the results, as the progress may be more evident in the early years of a child (Harris and Handleman, 2000).

Several studies have been conducted on the effectiveness of various intervention programmes for children with ASD but usually between studies there are significant discrepancies in outcome effectiveness (e.g. Tyminski & Moore, 2008; Pfeiffer et al, 2011). The variation in outcomes of different interventions creates complication in addressing questions about treatment effectiveness and leads to questions about the presence of some factors that may possibly influence the outcomes.

There has been agreement throughout the literature that individual characteristics influence treatment outcome, with a no "one treatment fits all" approach. For instance, White (2012) suggested that there is not one treatment that can suit all children with autism. However, there are very few studies that have focused on the role of individual family and child characteristics in treatment decisions (Schreibman, 2000). Some researchers have also reported that each child

with autism might respond differently to a treatment (Ingersoll et al, 2001). Most parents become overwhelmed when they are expected to choose the right treatment for their child since there are so many options. Parents of children with autism state that the treatments they choose, even if they are not supported by research, have been at some level effective for their children (Goin-Kochel et al, 2009). There is a growing need for research examining which services or combination of services are effective for children with autism based on their individual characteristics.

9.6 Psychotherapy and autism

The results of the present study provide original findings regarding the outcomes of psychodynamic/psychoanalytic psychotherapy for children with autism. As discussed in chapter five, many studies in the field of psychodynamic/psychoanalytic psychotherapy, have reported positive results of small scale or single case studies of children with autism receiving psychotherapy (Bromfield, 2000; Kobayashi 2000; Olesker, 1999; Vograft et al, 2007). Despite some of these positive anecdotes, there is a lack of rigorous research in the field of psychodynamic/psychoanalytic psychotherapy and the field has mixed status with respect to its scientific or clinical value. Few studies exist that evaluate the effectiveness of psychoanalytic/psychodynamic psychotherapy in everyday clinical settings and difficult-to-treat populations, like children with autism (Emmelkamp et al, 2014).

The results of this study are able to offer a better understanding of the impact of psychotherapy in comparison to other therapy contexts. The findings demonstrate how a psychodynamically - based approach can facilitate change when treating children with autism and suggest that psychodynamic treatment can be of value in

helping children with autism to advance their imagination, their vocabulary, their ability to interpret, recall and execute commands, their social communication skills and to reduce their stereotypic behaviours. These results are in accordance with the findings by Bromfield (2000) who demonstrated the therapeutic benefits of psychodynamic play when treating children with autism and those of Shuttleworth (1999) who suggested that psychoanalytic psychotherapy can help children with autism develop.

As already discussed, a subgroup analysis of the data showed that the group of children that had psychotherapy showed more imagination during play after one year, their language skills advanced and a reduction of their stereotypic behaviours was identified. These findings are similar to the findings of Fisher (2000) and Barrows (2002) who reported that the psychotherapeutic approach they followed proved to be helpful in facilitating the development of the child's language (Fisher, 2000; Barrows, 2002) and the child's imaginative play (Barrows, 2002).

The findings of this study also contribute to an understanding of the benefits of psychoanalytic/psychodynamic psychotherapy *per se*, and will be useful knowledge for parents and healthcare professionals in Greece. No published research was found investigating the use of this type of treatment with children with autism in Greece and to the author's knowledge there are no published statistics in regards to the number of individuals with autism receiving psychodynamic/psychoanalytic psychotherapy in Greece. Therefore, since autism seems to develop in a similar way between Greece and the UK, psychotherapy may also be an effective type of treatment for Greek children with autism as well, although this would need to be systematically investigated. While these results should be interpreted with caution, they are interesting nonetheless and should receive further attention.

The role of parents in this type of therapy is also of relevance. As discussed in a study by Carter et al (2011), children with autism tend to benefit from an intervention when their parents are included in the treatment and they work all together. Such parent involvement could be the substantial element for the success of the group of children that received psychotherapy. It is imperative, when planning an intervention for families of children with autism, to view the whole family as members of a system who influence each other in order to provide the most appropriate care to the child and the rest of the family (Hanson & Lynch, 2013). Future studies exploring the different aspects of interventions, e.g. parental involvement, are needed in order to recognize which elements of treatment are important for successful outcomes.

9.7 Limitations of the study

To the author's knowledge this study is one of the largest cross-national studies on this topic. However, with an even larger sample, subtler differences might have been revealed between the groups. Also, it would be interesting to assess a group receiving no intervention, but for ethical reasons, this would be unlikely in the countries considered here. Nonetheless, the inclusion of less well-developed countries might reveal differences in rate of change for untreated children. In this study the groups were posthoc found to match on measures at time 1 and the similarities were presented in the results chapter. Notwithstanding, it would clearly be advantageous to conduct a prospective study in which children with autism are randomised to intervention groups, and it is acknowledged that the present study explores the intervention context, rather than evaluating the effectiveness of therapy directly. This study goes some way to highlighting different therapy contexts but cannot make firm

conclusions about which changes were caused by intervention techniques. The fact that children's skills naturally change over a year should also be considered, as it will have affected the results along with the associated gains from therapies during that period. Without a comparison group of similar children receiving no treatment, the gains from each therapy cannot be conclusively attributed to each intervention respectively, as we need to consider the maturation effects. Additionally, a year might not be enough for a child with autism to change significantly, so it could be more useful to follow up the children every year for a longer period in order to have more robust findings. A longer follow-up period with additional assessment points would have provided a more accurate depiction of long-term effects of the different treatments, but the time factor had to be considered in this particular study. In addition, the issue of dosage of intervention was not sufficiently controlled because of the range of number of sessions of therapy made available to the children that in some cases might have not been enough for therapy gains to be measurable. Each therapy varied in length of sessions, total number of sessions and number of therapists involved, but this is usually what happens with children with autism. Missing data can be a methodological challenge in longitudinal studies. In this study, only 2 families were not retained at time 2, however it would have been preferable to have kept all participants in the study. Moreover, the fact that only private practices were included in the current study might have limited the generalizibilty of the results. This study was only focused on the private sector though in order to mirror the therapy choice that the parents made for their children, since in the public sector someone else makes that choice for you. Also, the inclusion of private practices made it easier to control for other therapies that the children might have at the same time and it made the groups across countries more homogenous by limiting the social disadvantage.

Issues of bias and subjectivity often arise when conducting this kind of research. The criteria used to recruit children from each group in this study were the same, in order to avoid selection bias. The fact that the researcher acted as the test administrator could be considered as a limitation. The validity of the study would have been increased if the researcher was not acting as the assessor. However, the investigator was not involved in the treatment of any of the participants in order to avoid person familiarity bias.

There are challenges when collecting and analysing data from countries with different sociocultural contexts and languages. Ungerson (1990) suggested that language skills are important and one might lose the culturally loaded meaning when in the process of translating data. However, in this study the dual cultural/linguistic background of the researcher assisted in minimising this potential problem. Another challenge that researchers face when conducting cross-national research is the issue of translation and adaptation of an instrument (Geisinger, 1994). Every time an instrument is adapted to a new linguistic context or is applied to a new target population, it is important to establish the same meanings or constructs with the same standards in that new target population (Geisinger, 1992). Techniques used in order to reduce translation-related problems may include back translation, consultation and collaboration with other people during the translation process (Ercikan, 1998). Personal communication and advice from researchers experienced in using non-standardized Greek versions of the assessment measures was provided to the researcher for the purposes of the current study. The tasks completed in the current study were based on previous Greek adaptations by Stavrakaki & Van der Lely (2010) and following advice from Stravrakaki and Kambanaros (personal communication). Taxitari, Kambanaros and Grohmann (2015) used a Greek Cypriot adaptation of the

CDI to explore children's language in a bilingual context. Stavrakaki & Van der Lely (2010) investigated whether deficits in the production and comprehension of pronouns in Greek children with SLI are best accounted for by domain-general or domain-specifics of language. In their study they used a non-standardized Greek version of the BPVS and a non-standardized Greek version of the CELF in order to measure the lexical and grammatical abilities of the children that participated in the study. They showed that this adapted measure was an accurate and valid tool within a Greek setting. The results are limited though by the use of measures that have not been normed for Greek children.

The fact that some of the measures are not validated in Greece challenges the reliability of the results and it would be beneficial to assess test-retest reliability in future studies in order to demonstrate the validity and stability of all the assessment tools used in the current study cross-natinonally. To that end, another limitation is the lack of pilot testing. A pilot test could have been undertaken in order to test adequacy of the research instruments and to test the research process. Additionally, the questionnaires that were completed by the clinicians, e.g. order of questions or range of answers could have been piloted. Pilot studies may identify potential problems but there is often a concern when data from the pilot study are included in the main results. In the current study it would not have been possible to exclude any potential pilot-study participants because it would have resulted in too small a sample in the main study.

9.8 Implications for practice

The diversity in the symptoms of children with autism has led to a vast amount of treatment options provided by different services across different settings.

Consequently, the choice for the parents has become even more difficult. The current study has provided important findings to parents of children with autism as it adds reassuring evidence that no one therapy context is associated with especially marked change. The pressure to choose the 'right' therapy often reported by parents of children with autism may therefore be reduced by the results of this study. There is also the other side of the coin; the specific finding could imply that the services involved might lack theoretical underpinning and that is the reason why children performed similarly across specific treatment contexts. However, it is also likely that the pathways to change are more complex than this study was able to investigate. For example, therapist questionnaires suggest that differently named therapies may be addressing similar target outcomes.

Based on the subgroup findings the speech and language therapy participants showed more widespread change on their communications skills; the children who received psychotherapy demonstrated an advantage in their imagination skills and the occupational therapy participants presented fewer stereotypical behaviours over time. The current study may have established that specific characteristics are linked with certain treatment approaches, but still it cannot be concluded that these treatments are being used to target these specific features. Further research exploring the individual characteristics of children with autism is needed in order to determine what treatment or combination of treatments work for each child. In addition, there is a need to focus on the recognition of crucial treatment elements in order to identify what makes each therapy successful.

One of the most daunting challenges faced by parents and professionals working with children with autism is knowing which of the countless number of treatments or interventions will be best. Of the many interventions and services

currently in use Mills & Wings (2005) noted that in many cases the treatments proposed are determined more by the interests and belief system of the therapist, than the condition of the child. An internet survey in 2006 in the UK provided some insight into the type and number of interventions parents were using with their children with ASD. They found, that on average, depending on the type of ASD diagnosis, children were receiving at that time between four and six different interventions and had tried between seven and nine (Goin-Kochel et al, 2006). As we have yet no definitive way of telling which child will benefit from which therapy parents are likely to try a variety of approaches to ascertain which, if any, are beneficial for their child. The present study raises awareness of other types of therapy that are available in terms of intervention and parents are given better insight in different therapy choices.

A study by Bowker et al (2011) showed that most families followed multiple treatment choices and the most important factor that led them to terminate an intervention or try another one was the lack of their child's improvement. Parents also look for alternative approaches when the more traditional ones do not seem to help with their children's symptoms. With respect to parents' treatment selection for their children with autism, there is growing evidence that empirical support is not the most influential factor (Wong & Smith, 2006; Green et al, 2006; Christon et al, 2010; Mandell & Novak, 2005). Relatively few empirical studies have been conducted on the topic and the findings are inconsistent. With respect to the influence of children's characteristics on parents' treatment selection, Goin Kotchel et al (2006) suggested that younger children with autism were more likely to receive behavioural treatments and older ones to receive psychopharmacological ones. However, Dardennes et al (2011) did not report any links between children's ages and the types of treatment that

their parents chose. Also, Dardennes et al (2011) did not find a relation between the severity of the children's symptoms and the types of treatment their parents chose.

Many factors have been suggested to influence parental choice of interventions. These include cultural context (Jegatheesan et al, 2010, Levy et al, 2003); parents' beliefs about the cause, course and symptoms of the disorder (Mandell & Novak, 2009); worldviews (King et al, 2009); needs of the child and family (Astin, 1998); past experiences with healthcare providers (Mandell & Novak, 2009); parental and family characteristics (Hall, 2012); parental stress (Konstantareas and Lampropoulou, 1995); parents' cognitive representations of autism (Al Anbar et al, 2010) and the trust towards the professionals that provide the recommendations (Harrington et al, 2006). Accordingly, it is important for professionals to explore parents' beliefs about their child's symptoms and their expectations for the course of the disorder and to take into account that their cultural beliefs might influence their interpretation of their child's autism (Hebert & Koulouglioti, 2010).

Another issue that parents of children with autism face is the choice between private or public services and their understanding of how the treatment path they follow may be different if they decide to spend their own money. The funding for services for children with autism is a big concern for families, private and public insurers and policymakers (Chatterji et al, 2015). Treatment for autism is considered to be very costly that also depends on the severity of the symptoms. There is continuous debate with respect to health insurance and what services should be covered for children with autism (Holland, 2010). In addition, private insurance plans do not include coverage for all types of intervention for autism (Chatterji et al, 2015). A recent study examining characteristics of children with autism in Greece identified that 78% of the children in the study had private speech, occupational or music

therapy at least once a week (Stampoltzis et al, 2012). Occupational therapy and speech and language therapy are typically included in the annual cost of special education services, but there are individuals who choose to go privately (Kornack et al, 2014). This could be explained due to the long waiting lists in the public sector. Families of children with autism face different financial costs based on the severity of their child's symptoms, the country they live in, the extent of comorbid diagnoses and the age of their child (Kornack et al, 2014).

A study by Irvin et al (2012) suggested that another factor that influences parents of children with autism and leads them toward the private sector is their levels of stress. It was found in their study that the parents that were more stressed were more likely to choose private therapy for their children. Irvin et al (2014) offered as an explanation to this finding the fact that these parents had children with more severe symptomatology and it was more stressful and this might have made them utilize additional services for their children. Furthermore, literature suggests (Thomas et al, 2012) that parents of children with autism have more difficulties in accessing services than parents of children with other types of special healthcare needs and that they are more likely to be dissatisfied with services rendered (Montes et al, 2009). Consequently, parents might opt out of these services and seek private ones.

A further and important implication for practice is how the information from this study can help professionals who work with children with autism further their understanding of the disorder and how it manifests through time in order to provide appropriate services based on each child's needs. Moreover, the analysis implied that certain characteristics tend to be associated with specific treatment types. Namely, speech and language therapy seems to have contributed more to the advancement of children's language skills; psychotherapy participants showed significant greater

increase in imagination; and the stereotypic behaviours of the occupational therapy group reduced significantly over time. It was also demonstrated that all participants showed improvements in the realms of communication.

This finding leads us to believe that sometimes the most effective course of treatment is a combination of therapies depending on the individual needs of each family. The conclusions from these results could assist in creating a combined treatment plan that will provide desired outcomes. A multidisciplinary approach might be able to bridge the gap between clinical services, families and research. This highlights the importance of collaboration between professionals of different clinical backgrounds and promotes interprofessional practice in order to provide the most effective course of treatment. It calls upon professions to exchange knowledge, and to combine their expertise to plan and provide co-ordinated services for better developmental outcomes for children with autism.

Dillenburger et al (2014) have reported that sometimes professionals do not agree with each other regarding the choice of treatment plan parents should follow after the initial diagnosis of autism. A multidisciplinary approach is recommended by the National Institute for Clinical Excellence (NICE, 2013) to professionals who work with children in the spectrum. If different areas of expertise are combined, rigid professional boundaries get extended and the benefits increase (Dillenburger et al, 2014). The present thesis promotes further reflection upon the benefits for children with autism when combining treatments.

The UK's National Autism Plan for Children (NIASA, 2003) and the National Council for Special Education (NCSE) report (Parsons et al, 2009) highlight the importance of a multidisciplinary approach for professionals working with individuals with autism. According to Parsons et al (2009) this type of intervention practice is

crucial for families of children with autism because each practice targets different areas of development and help children improve a variety of skills. Families of children with autism can be provided with relevant information about different disciplines from various professionals and they can help them decide the ones more appropriate for them. However, it is important for the professionals to be familiar with many treatment options in order to guide the families accordingly (Gabovitch & Curtin, 2009).

Upton & Upton (2006) reported that sometimes there is diversity among the opinions of professionals towards various interventions and they often tend to turn into their own discipline. Nevertheless, Reichow and Volkmar (2010) suggest that it is important for clinical and research purposes to incorporate research across various practices. Harbin et al (2000) noted that in order to provide effective family-centred care to children with autism, it is imperative for professionals to adapt services to the needs of every family and to respect each family's exclusive features.

9.9 Implications for research and future directions

The purpose of conducting this cross-national study was to explore the processes that construct national differences in the area of autism, and attempt to identify and discuss the differences and similarities in the manifestation of autism across the two countries. In cross-national research the aim is not just to confirm that two systems, for example, have similarities and differences regarding a single variable but also to evaluate the similarities and differences among processes or relationships across social systems (Lee, 1984).

Cross-national research contributes to understanding better the differences and the similarities among countries. It also helps in gaining awareness of phenomena in

different countries and in searching for clarifications about their existence (Chamberlayne & King, 1996). When data is collected from another country along with one's own country the results may offer new perspectives to the research conducted. It is not necessary for a cross-national study to be fully comparative. In some cross-national studies each country's wider social context is compared in order to explain data (Hantrais & Mangen, 1996). In this study the cross-national approach is intended to give some suggestions about the way childhood autism is treated in each country and enable comparisons to be made. The importance of doing a cross-national study is that you see the phenomenon in a broader perspective, by concentrating on the differences as well as similarities that appear across the countries.

According to Hantrais (1999) cross-national comparisons offer a sense of objectivity because it is possible for researchers to have their own personal view of their society and to be certain that the way things run in their country is the best. Conducting a cross-national study may help the researchers to distance themselves and to see things more objectively. It becomes easier then to accept differences and to analyse the different cultural settings from another angle. This way, researchers are able to identify potential gaps in knowledge, differences and similarities in experiences across countries and in perceptions of issues and societies (Bird et al, 2010). According to Gonzalez Block (2006) health systems research across countries can increase successful interventions and makes the health systems stronger. There is a growing need to gather information about autism from all countries and to examine how differences might relate to different health provision and different attitudes towards the disorder.

The ways in which different countries manage autism spectrum disorders are

interesting and the literature review conducted for this research has shown that there is a limited understanding of cultural differences. The results of this study showed that children with autism are developing in a very similar way across the two countries. There is very little known about the results of psychotherapy in Greece and since autism seems to develop in a similar way between Greece and the UK, psychotherapy may also be an effective type of treatment in the Greek population as well, although this would need to be systematically investigated. Furthermore, with respect to the academic knowledge this research adds to the general understanding of autism, as there is a growing need to gain a better understanding of how this disorder manifests through time. The results of the present study can inform the academic audience of the general development of children with autism over time and of the outcomes of psychotherapy for children with autism since there is not enough robust evidence in the literature.

Most children will probably make some progress in the early stages of an approach regardless the type of treatment provided (Jordan et al, 1998). The current study adds to the existing knowledge base since the long-term effects of different interventions on similar children were explored and similar conclusions were drawn. An area for further research has been identified to explore service choice and how it is linked with change, for example how a particular kind of therapy might help certain skills develop further. The present study can be considered as a stepping-stone for further exploration of the different effect that various interventions have on children with autism. Also, we could conduct research in the public sector and compare the progress of children being treated in the private sector. Future studies could make private vs public healthcare comparisons and could focus on the elements of specific service use. In addition, future research should investigate the link between individual

therapy features and the developmental outcomes among children with autism and explore interventions implemented at a greater intensity over a longer period of time.

It would be useful to conduct a randomized control study in the future, in order to focus more on the content of therapies, since it was not intended to assess the effectiveness of the therapeutic interventions in this study. There is limited understanding of how to target the individual symptoms that a child with autism presents with the appropriate course of treatment. Therefore, further research is needed exploring the individual characteristics of children with autism and how they are linked with each type of treatment. Moreover, if the results of this study were replicated in research on a larger scale then it would be interesting to explore further which of the children's skills advance more after receiving the differing types of intensive intervention mentioned above. For instance, the children that showed change in their imagination over time were only the ones receiving psychotherapy, so an extension of this study could lead to a better understanding of these findings. Providing professionals with information on the outcomes of psychotherapy may help to further clarify our understanding of the use of this type of treatment when working with children with autism. According to Cuvo & Vallelynga (2007) the diversity in the clinical picture of autism leads to a greater need for individualized interventions and the heterogeneity found across ASD symptoms makes every intervention practice more of a challenge (Fountain et al, 2012).

The present thesis provides a platform for future research on the adaptation of a treatment according to the characteristics of the child. Green et al (2006) conducted an Internet survey on a sample of 552 parents of children with autism to determine the different treatments that they use. Based on the results there were 108 different programs, procedures and approaches in use or were in use at some point in the past.

Similar findings are shared by Goin-Kochell et al (2009) and it was also reported by parents that in cases that the symptoms were more severe parents tended to use more services. Based on the results of studies that explored reasons why parents choose certain treatments over others, lack of funds, availability and treatment efficacy help parents make the decision to start or discontinue treatments (Bowker et al, 2011). However, as it is mentioned by Schreibman and Koegel (2005) there are not many interventions that are supported by empirical research. Future empirical studies should explore the effectiveness of the different types of treatment.

If certain skills change after particular types of therapy then clinicians can use this information in their practice and multidimensional treatment might be required in order to make a real difference to this group. The individual components that each service uses yield important information about the focus of each intervention practice. In the future the combination of these services could also be investigated as a whole to see how effective it is. According to Schrek & Mazur (2008) parents of children with autism often combine different treatments and the cooperation between parents and professionals is considered a vital part for the progress of children. A greater understanding of each treatment programme may help to identify more effective ways to contribute to the positive progress of children with ASD. More research is needed to assess multidisciplinary interventions, how they affect children's progress over time, to explore the perceptions and partnerships among professionals from different disciplines and to investigate the long-term benefits or challenges of this type of treatment plan.

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APPENDICES

Appendix I

Questionnaires

A) SLT group-UK

Instructions: Please answer the following questions by writing in the box provided or by circling the answer of your choice

1. What is the nature of the intervention you provide?

Speech and language therapy

2. What kind of assessment do you practice? What combination of therapy was used?

Speech and Language Therapy AAC Autism diagnostics

3. Do you use standardised assessments?

YES NO

4. What kind of other interventions are often provided to the individuals with ASD you work with (at the same time as your intervention)?

Tick all that apply

☐Speech and Language Therapy
☑ ABA
☑ Occupational Therapy
☐ Psychotherapy
☐ I don't know
☐ Other

5. Do you work in collaboration with the other professionals involved in the support of the individuals with ASD you work with?

YES NO

6a. What is the usual frequency of the sessions?

☐ **once a day**
☑ **2 or 3 times a week**
☑ **once a week**
☐ **once a month**
☐ **less than once a month**

6b. What is the usual duration of the sessions?

☐ **5 or 6 hours**
☐ **3 or 4 hours**
☐ **2 or 1 ½ hours**
☐ **1hour**
☑ **less than an hour**

7. Do you work in collaboration with the parents?

yes

8. Where does your intervention take place?

Private practice

9. To what extent can an intervention be transferred for use in other settings?

the techniques can be used at various places

10. What areas do the children you treat usually progress in?

Social, communication, behavioural areas

11. If you noticed any progress, was it maintained after the intervention?

YES NO

12. Do you aim to help children communicate both verbally and nonverbally?

YES NO

13. Do you focus on the way children respond emotionally?

YES NO

14. Do you work on the child's ability to communicate wants and needs?

YES NO

15. Do you work with alternative communication systems?

YES **NO**

16. We focus on:

☑ vocabulary
☑ syntax
☑ semantics
☑ articulation
☑ prosodic features (intonation/volume/tone of voice)
☑ abnormal/repetitive use of language

17. We work on the development of:

☑ interaction and communication skills
☑ receptive language skills
☑ play skills

☑ use and understanding of body language and facial expressions
☑ conversation skills
☑ higher level of language skills (e.g. humour)
☑ social skills
☑ the child's capacity for self expression and to reason and problem solve
☐ the quality of child's interactions
☐ the child's ability to cope with everyday situations
☐ the child's awareness of their difficulties and emotions
☐ the child's understanding of social cues and conventional behaviour
☐ sharing and taking turns

18. Do you help the child cope with anxiety?

YES NO

19. We use:

☑ visual aids
☑ behavioural scripts
☑ social stories

20. Do you assist a child to develop new skills?

YES NO

21. Do you help parents learn how to interact and play with their child?

YES NO

22. We focus on:

☐ self-care activities
☐ activities to improve the child's fine and gross motor skills
☑ behaviour management
☐ strategies and interventions that address sensory difficulties

23. Do you work with other carers and professionals (e.g. teachers) to provide them with strategies to assist the child function better in the home, school and other environments?

YES NO

Please use this space to write anything you would like to add, to specify, or to make any comment on this questionnaire

B) Psychotherapy group-UK

Instructions: Please answer the following questions by writing in the box provided or by circling the answer of your choice

1. What is the nature of the intervention you provide?

The Clinic provides assessment and treatment to parents with infants and toddlers and consultations to primary care givers. The approach is psychodynamic.

2. What kind of assessment do you practice? What combination of therapy was used?

Our approach is psychodynamic. In other words, we place an emphasis on relationships. Our approach is based upon "developmental" psychoanalysis, yet also incorporates learning from several other fields, including neurobiology, psychodynamics, behavioural, cognitive, humanistic, bio-psychological, and socio-cultural therapies.

3. Do you use standardised assessments?

YES **NO**

4. What kind of other interventions are often provided to the individuals with ASD you work with (at the same time as your intervention)?

Tick all that apply

☑Speech and Language Therapy
☐ ABA
☑ Occupational Therapy
☐ Psychotherapy

☐ **I don't know**
☐ **Other**

5. Do you work in collaboration with the other professionals involved in the support of the individuals with ASD you work with?

YES NO

6a. What is the usual frequency of the sessions?

☑ **once a day**
☑ **2 or 3 times a week**
☑ **once a week**
☐ **once a month**
☐ **less than once a month**

6b. What is the usual duration of the sessions?

☐ **5 or 6 hours**
☐ **3 or 4 hours**
☐ **2 or 1 ½ hours**
☑ **1hour**
☐ **less than an hour**

7. Do you work in collaboration with the parents?

We explore the world from the points of view of both the child and the family and we work with the whole family.

8. Where does your intervention take place?

At a private setting.

9. To what extent can an intervention be transferred for use in other settings?

Our aim is to give the parents the tools they need for the everyday life

10. What areas do the children you treat usually progress in?

Social, communication, imagination, sensorial and affect

11. If you noticed any progress, was it maintained after the intervention?

YES NO

12. Do you aim to help children communicate both verbally and nonverbally?

YES NO

13. Do you focus on the way children respond emotionally?

YES NO

14. Do you work on the child's ability to communicate wants and needs?

YES NO

15. Do you work with alternative communication systems?

YES **NO**

16. We focus on:

☐ **vocabulary**
☐ **syntax**
☐ **semantics**

☐ **articulation**
☐ **prosodic features (intonation/volume/tone of voice)**
☐ **abnormal/repetitive use of language**

17. We work on the development of:

☑ **interaction and communication skills**
☐ **receptive language skills**
☑ **play skills**
☑ **use and understanding of body language and facial expressions**
☑ **conversation skills**
☑ **higher level of language skills (e.g. humour)**
☑ **social skills**
☑ **the child's capacity for self expression and to reason and problem solve**
☑ **the quality of child's interactions**
☑ **the child's ability to cope with everyday situations**
☑ **the child's awareness of their difficulties and emotions**
☑ **the child's understanding of social cues and conventional behaviour**
☑ **sharing and taking turns**

18. Do you help the child cope with anxiety?

YES NO

19. We use:

☐ **visual aids**
☐ **behavioural scripts**
☐ **social stories**

20. Do you assist a child to develop new skills?

YES NO

21. Do you help parents learn how to interact and play with their child?

YES NO

22. We focus on:

☐ **self-care activities**
☐ **activities to improve the child's fine and gross motor skills**
☑ **behaviour management**
☐ **strategies and interventions that address sensory difficulties**

23. Do you work with other carers and professionals (e.g. teachers) to provide them with strategies to assist the child function better in the home, school and other environments?

YES NO

Please use this space to write anything you would like to add, to specify, or to make any comment on this questionnaire

C) SLT group-Greece

Instructions: Please answer the following questions by writing in the box provided or by circling the answer of your choice

1. What is the nature of the intervention you provide?

Speech and language therapy

2. What kind of assessment do you practice? What combination of therapy was used?

3. Do you use standardised assessments?

YES NO

4. What kind of other interventions are often provided to the individuals with ASD you work with (at the same time as your intervention)?

Tick all that apply

☐Speech and Language Therapy
☐ ABA
☑ Occupational Therapy
☐ Psychotherapy
☐ I don't know
☐ Other

5. Do you work in collaboration with the other professionals involved in the support of the individuals with ASD you work with?

YES NO

6a. What is the usual frequency of the sessions?

☐ once a day
☑ 2 or 3 times a week
☐ once a week
☐ once a month
☐ less than once a month

6b. What is the usual duration of the sessions?

☐ 5 or 6 hours
☐ 3 or 4 hours
☐ 2 or 1 ½ hours
☐ 1hour
☑ less than an hour

7. Do you work in collaboration with the parents?

yes

8. Where does your intervention take place?

Private speech and language therapy centre

9. To what extent can an intervention be transferred for use in other settings?

To a satisfying level under the right circumstances

10. What areas do the children you treat usually progress in?

Duration of concentration, speech production, development of descriptive speech and communication

11. If you noticed any progress, was it maintained after the intervention?

YES NO

12. Do you aim to help children communicate both verbally and nonverbally?

YES NO

13. Do you focus on the way children respond emotionally?

YES NO

14. Do you work on the child's ability to communicate wants and needs?

YES NO

15. Do you work with alternative communication systems?

YES **NO**

16. We focus on:

☑ **vocabulary**
☑ **syntax**
☐ **semantics**
☑ **articulation**
☑ **prosodic features (intonation/volume/tone of voice)**
☐ **abnormal/repetitive use of language**

17. We work on the development of:

☑ **interaction and communication skills**
☑ **receptive language skills**
☑ **play skills**
☐ **use and understanding of body language and facial expressions**
☑ **conversation skills**
☐ **higher level of language skills (e.g. humour)**
☑ **social skills**
☑ **the child's capacity for self expression and to reason and problem solve**
☐ **the quality of child's interactions**
☐ **the child's ability to cope with everyday situations**
☐ **the child's awareness of their difficulties and emotions**
☐ **the child's understanding of social cues and conventional behaviour**
☐ **sharing and taking turns**

18. Do you help the child cope with anxiety?

YES NO

19. We use:

☐ **visual aids**
☑ **behavioural scripts**
☑ **social stories**

20. Do you assist a child to develop new skills?

YES NO

21. Do you help parents learn how to interact and play with their child?

YES NO

22. We focus on:

☑ **self-care activities**
☐ **activities to improve the child's fine and gross motor skills**
☑ **behaviour management**
☐ **strategies and interventions that address sensory difficulties**

23. Do you work with other carers and professionals (e.g. teachers) to provide them with strategies to assist the child function better in the home, school and other environments?

YES NO

Please use this space to write anything you would like to add, to specify, or to make any comment on this questionnaire

<u>D) OT group-Greece</u>

Instructions: Please answer the following questions by writing in the box provided or by circling the answer of your choice

1. What is the nature of the intervention you provide?

Occupational therapy

2. What kind of assessment do you practice? What combination of therapy was used?

Assessment: observation of structured and free play, testing, background information, sensorial profile Treatment: sensory integration, TEACCH, Sherborn

3. Do you use standardised assessments?

YES NO

4. What kind of other interventions are often provided to the individuals with ASD you work with (at the same time as your intervention)?

Tick all that apply

☑ Speech and Language Therapy
☐ ABA
☐ Occupational Therapy
☐ Psychotherapy
☐ I don't know
☐ Other

5. Do you work in collaboration with the other professionals involved in the support of the individuals with ASD you work with?

YES NO

6a. What is the usual frequency of the sessions?

☑ once a day
☑ 2 or 3 times a week
☐ once a week
☐ once a month
☐ less than once a month

6b. What is the usual duration of the sessions?

☐ 5 or 6 hours
☐ 3 or 4 hours
☐ 2 or 1 ½ hours
☐ 1hour
☑ less than an hour

7. Do you work in collaboration with the parents?

yes

8. Where does your intervention take place?

Private centre

9. To what extent can an intervention be transferred for use in other settings?

To a small degree at home

10. What areas do the children you treat usually progress in?

Fine and gross motor skills/sensory deficits/behaviour management/self-control/praxis/cognitive skills (concentration, memory, visual skills)/everyday life skills

11. If you noticed any progress, was it maintained after the intervention?

YES NO

12. Do you aim to help children communicate both verbally and nonverbally?

YES **NO**

13. Do you focus on the way children respond emotionally?

YES NO

14. Do you work on the child's ability to communicate wants and needs?

YES NO

15. Do you work with alternative communication systems?

YES NO

16. We focus on:

☐ vocabulary
☐ syntax
☐ semantics
☐ articulation
☐ prosodic features (intonation/volume/tone of voice)
☐ abnormal/repetitive use of language

17. We work on the development of:

☑ interaction and communication skills
☐ receptive language skills
☑ play skills
☐ use and understanding of body language and facial expressions
☑ conversation skills
☐ higher level of language skills (e.g. humour)
☑ social skills
☑ the child's capacity for self expression and to reason and problem solve
☑ the quality of child's interactions
☑ the child's ability to cope with everyday situations
☑ the child's awareness of their difficulties and emotions
☑ the child's understanding of social cues and conventional behaviour
☑ sharing and taking turns

18. Do you help the child cope with anxiety?

YES NO

19. We use:

☑ visual aids
☑ behavioural scripts

☐ **social stories**

20. Do you assist a child to develop new skills?

YES NO

21. Do you help parents learn how to interact and play with their child?

YES NO

22. We focus on:

☑ **self-care activities**
☑ **activities to improve the child's fine and gross motor skills**
☑ **behaviour management**
☑ **strategies and interventions that address sensory difficulties**

23. Do you work with other carers and professionals (e.g. teachers) to provide them with strategies to assist the child function better in the home, school and other environments?

YES NO

Please use this space to write anything you would like to add, to specify, or to make any comment on this questionnaire

Appendix II

CITY UNIVERSITY LONDON

School of Community and Health Sciences

Research Office
20 Bartholomew Close
London EC1A 7QN

Tel: +44 (0) 20 7040 5704

www.city.ac.uk

Ref: PhD/10-11/02

1 July 2011

Dear Kristi / Julia / Nicola

Re: A cross-national retrospective evaluation study of interventions in childhood autism

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely

Alison Welton

Alison Welton
Research Governance Officer

[redacted]

Appendix III

Information letter

Dear Parent

A cross-national study of childhood autism

I am writing to invite you and your child to take part in a study exploring different approaches of treating childhood autism in England and in Greece. It is important to assess what treatments work for which children and to identify those characteristics that predict responsiveness to specific programs/approaches.

Children with autism who had different types of treatment will be taking part. The service where your child was offered help and City University London are working together on the study.

What will your child do?

We are interested to see how children with autism progress after receiving intensive therapy. We are also interested to find out which children benefit most from each intervention and what the differences are in their communication skills after using different interventions.

To help us achieve our goal we would like to measure your child's progress twice over a period of two years. Each time the researcher will spend about 1 hour with you and your child for each direct assessment and also your child will be observed using the ADOS tool (the **Autism Diagnostic Observation Schedule** is an instrument for diagnosing and assessing Autism). The researcher will have a police check and be very used to working with young children, including those with communication problems.

What will you be asked to do?

We would like you to complete two questionnaires twice for a two-year period. These will be about your child's social and communication skills.

Who will get the information from the study?

At the end of the study you will be provided with a summary of the results and the actual scores upon request. The information and scores from the study will not be shared with any other children or families.

In any reports, the scores will always be looked at as group information. So, it might say 'Most of the children's language improved during speech and language therapy'. At no point will your family or child's name be kept on a computer or written into a public report. All researchers must keep to the Data Protection Act 1998. All data will be kept in locked filing cabinets and spreadsheets will be password protected. No personal information will be shared outside of the research study.

Can you change your mind after you have said yes?

You and your child are free to change your mind at any time and without giving any reason and we will completely understand. If your child looks upset during the tasks we will stop. You can also speak to someone else apart from the researchers about the study if you are not happy. You can phone or write to the Secretary of the Research Ethics Committee. That person is: Anna Ramberg, ([redacted], Secretary to Senate Research Ethical Committee, City University, Northampton Square, London EC1V 0HB, Tel: [redacted] You need to give the name of the study as: A cross-national study of childhood autism.

In Greece you can contact: Dimitrios Zafeiriou [redacted], MD, PhD Child Neurologist Assistant Professor of Child Neurology and Developmental Pediatrics, 1st

department of paediatrics, Aristotle University of Thessaloniki, Egnatia St. 106 54622, Greece, Tel: [redacted]

It is really important to remember that you can say no to this evaluation study without affecting your child's involvement in any of the intervention centres. Your child can still continue even without taking part in this evaluation study and no-one will mind.

What to do next

If you are happy for your child to take part, please fill in and sign the two forms with this letter and return it to the…. or post it back to us in the envelope.

Taking part in the study will help us provide information to you, the services involved and the academic audiences about the outcomes achieved using the different ways of treating childhood autism and to compare data on the progress made by each child over the course of research in the social, emotional and communication area. Parents quite often find great difficulty in making up their mind which is the most appropriate approach for their child, and interventions often incur financial cost to families. Through the study different programmes will be explored and further knowledge will be gained about the progress of the children involved and about the strengths and weaknesses of these programmes.

Many thanks for your help,

Maria Krystallia Poppi [redacted]
Tel: [redacted]
Nicola Botting ([redacted])
Nicola Botting PhD
Language and Communication Science
City University, London, EC1V0HB
Joint Research Director and Senior Tutor for Researc

Appendix IV

Consent Form

A cross-national study of childhood autism

I have read the information letter, which I can keep

I have had the chance to talk more with someone about the study if I wanted to

I understand that any information from the study will be kept private and that no-one will be able to tell how my child did on the tasks except the research team and the services involved with my consent

My child's name won't be written into any reports or be kept on any computer files

I agree to City University London keeping and using this anonymous information for this study

I understand that the answers I give and the results of my child's tests will be used only for the study

I only agree if the City University London keeps its promise to stick to the rules of the Data Protection Act 1998

I understand that no-one will visit me at home or contact me at my home address without my consent.

I understand that agreeing to take part means that I am happy to:

- Let my child complete the tests given by the researcher on 2 occasions in 3 years

- This will take place at the institute where my child had/has therapy

Please indicate below your agreement

1. Have you read the Information Letter?	**YES/NO**

2. Have you been told enough information about the study?	**YES/NO**
3. Do you understand that you do not need to take part in the study and if you do take part you and your child can change your mind and drop out: - at any time (even after the study has started) - without having to give reason for dropping out - and without disadvantage to you or your child?	**YES/NO**
4. Do you agree to take part in this study?	**YES/NO**

Your child's name:…….
Your child's date of birth:…….
Your name:……
Signed:……Date:……

Please give this back to Maria Krystallia Poppi
This project has been approved by the SCHS Research Ethics Committee at City University London

Appendix V

Table 23. Individual participant data at time 1

Groups	AGE (in months)	Gender	SCQ	ADOS-Com	ADOS-Soc	ADOS-Imag	ADOS-Ster	C&FD	FS	BPVS	Raven	CDI-U	CDI-U/S
1	66	male	9	6	5	0	1	5	0	15	0	302	92
1	50	male	10	4	2	1	2	18	16	45	9	416	416
1	73	female	15	4	8	1	4	9	4	26	11	13	387
1	47	male	12	4	1	1	2	7	2	25	5	60	356
1	85	male	14	6	6	1	5	21	12	31	21	416	416
1	64	male	9	5	4	2	3	36	7	65	14	416	416
1	82	male	4	3	5	2	4	42	28	68	17	416	416
1	96	male	9	2	7	1	4	35	25	72	15	416	416
1	70	male	15	3	6	2	3	17	19	59	11	416	416
1	52	male	11	3	3	1	3	19	10	42	5	416	416
2	42	male	23	8	12	4	6	0	0	2	0	120	89
2	47	male	25	8	10	3	5	0	0	5	0	70	40
2	68	male	11	6	9	2	6	17	17	54	16	416	416
2	82	male	18	6	7	0	3	24	20	65	26	416	416
2	59	male	1	3	2	0	1	14	6	32	19	416	416
2	96	male	17	7	11	2	6	14	0	54	4	63	347
2	40	male	9	3	5	2	2	3	0	8	0	82	318
2	57	male	7	4	3	0	3	21	12	58	17	416	416
2	48	male	10	3	2	1	2	19	14	40	6	416	416
2	54	male	14	4	3	1	3	15	5	52	9	39	377
3	54	male	11	7	4	0	4	12	4	41	20	416	416
3	96	male	11	1	5	1	3	43	32	85	21	416	416
3	36	female	1	5	3	0	0	0	0	26	11	400	387
3	60	male	11	5	6	2	4	14	6	37	12	416	356
3	102	male	3	1	3	1	1	48	42	92	30	416	416

3	65	male	27	13	14	2	6	0	0	34	0	351	318
3	90	male	18	4	6	1	2	18	18	62	23	416	416
3	30	male	13	8	9	3	4	0	0	12	0	391	52
3	36	male	16	8	11	2	4	0	0	21	0	416	198
3	31	female	23	7	12	4	6	0	0	0	0	298	43
4	38	male	24	9	13	4	6	0	0	2	0	416	154
4	51	female	9	7	10	1	2	12	0	22	3	416	196
4	84	male	16	6	8	2	5	14	0	38	16	416	28
4	96	male	15	6	7	2	3	24	11	58	21	416	416
4	72	male	13	7	9	4	2	9	2	35	10	416	416
4	108	male	12	5	4	2	0	32	26	77	23	416	416
4	93	male	9	3	5	2	2	20	9	51	14	416	416
4	61	male	11	4	3	1	1	16	4	33	8	416	416

*1-SLT-GR
*2-OT-GR
*3-PSYCH-UK
*4-SLT-UK

Appendix VI

List of assessment measures (chapter 2 and chapters 4,5,6)

ABC	Aberrant Behaviour Checklist
ABCL	Adult Behaviour Checklist
ADOS	Autism Diagnostic Observation Schedule
ADI-R	Autism Diagnostic Interview-Revised
ALS	Asher Loneliness Scale
ASQ	Autism Screening Questionnaire
ATEC	Autism Treatment Evaluation Checklist
BASC	Behaviour Assessment System for children
BPVS	British Picture Vocabulary Scale
BRIAAC	Behaviour Rating Instrument for Autistic & Atypical Children
BSID	Bayley Scales of Infant Development
CASL	Comprehensive Assessment of Spoken Language
CARS	Childhood Autism Rating Scale
CBC	Child Behaviour Checklist
CBS	Checklist and Behaviour Sample
CBCL	Child Behaviour Checklist
CDER	Client Development Evaluation Report
CDI	MacArthur Communicative Development Inventory

CELF- R	Clinical Evaluation of Language Fundamentals – Revised
CES-D	Centre for Epidemiologic Studies Depression Scale
CSBS DP	Communication and Symbolic Behaviour Scales Developmental Profile
CSS	ADOS calibrated severity scores
DAS	Differential Ability Scales
DBC	Developmental Behaviour Checklist
DIGS	Diagnostic Interview for Genetic Studies
DISCO	Diagnostic Interview for Social and Communication Disorders
EAP	Brunet Lezine Revise´: Echelle de developement psychomoteur de la premiere enfance, Paris
EDR	Early Development Interview
EOWPVT	Expressive One-Word Picture Vocabulary Test-Revised
ESCS	Early Social Communication Scales
EVT	Expressive Vocabulary Test
FACES	Family Adaptability and Cohesion Evaluation Scales
FAST-R	Functional Assessment Screening Tool-Revised
FIGS	Family History Interview for Genetic Studies
FMSS	Five Minute Speech Sample
GAS	Goal Attainment Scale
GMDS	Griffiths Mental Development Scales

HCAM	Hampstead Child Adaptation Measure
HETA	Hopes and Expectations for Treatment Approach
K-ABC	Kaufman Assessment Battery for Children
Leiter	Leiter International Performance Scale
M-CHAT	Modified Checklist for Autism in Toddlers
MIS	Motor Imitation Scale
MPR	Merrill-Palmer-Revised Scales of Development
MSEL	Mullen Scales of Early Learning
NARA	Neale Analysis of Reading Ability
PAF	Proximal attention-following procedure
PAI	Positive Affect Index
PDDST	Pervasive Developmental Disorder Screening Test
PEP-R	Psycho-Educational Profile-Revised
PL-ADOS	Pre-Linguistic Autism Observation Schedule
PLS	Preschool Language Scale
PPVT	Peabody Picture Vocabulary Test
PDS	Pubertal Development Scale
PDDBI	Pervasive Developmental Disorders Behaviour Inventory
PEDI	Paediatric Evaluation of Disability Inventory
PSI	Parenting Stress Index

QABF	Questions About Behavioural Functions
QNST-II	Quick Neurological Screening Test
Raven's	Raven's Progressive Matrices
RBQ	Repetitive Behaviour Questionnaire
RBS-R	Repetitive Behaviour Scale – Revised
RDLS	Reynell Developmental Language Scales
SIPT	Sensory Integration and Praxis Test
SSB-2	School Social Behaviour Scale
SSP	Short Sensory Profile
SPM	Sensory Processing Measure
SRS	Social Responsiveness Scale
STAT	Screening Tool for Autism in Two-year-olds
SBS	Stereotyped Behaviour Scale
SCQ	Social Communication Questionnaire
SRS	Social Responsiveness Scale
SGM	Story Grammar Marker
SIB-R	Scales of Independent Behaviour-Revised
SICD	Structured Clinical Interview for DSM
SICD–R	Sequenced Inventory of Communicative Development–Revised
TLC	Test of Language Competence

TOPL	Test of Pragmatic Language
VABS	Vineland Adaptive Behaviour Scale
VSC	Vineland Screener
WAIS-R	Wechsler Adult Intelligence Scale-Revised
WISC	Wechsler Intelligence Scale for Children
WPPSI-R	Wechsler Preschool and Primary Scale of Intelligence
WPPSI-R	Wechsler Pre-school and Primary Scale of Intelligence-Revised
WJ–R	Woodcock–Johnson–Revised
WIAT	Wechsler Individual Achievement Test
WOTA	Water Orientation Test Alyn
WRIT	Wide Range Intelligence Test
Y-BOCS	Yale-Brown Obsessive Compulsive Scale