Validation of a Screening Instrument for Autism Spectrum Disorders among Primary School Children in Ireland

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I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of PhD is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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List of Abbreviations

ASD	- Autism Spectrum Disorder
AS	- Asperger Syndrome
AD	- Autistic Disorder
CA	- Childhood Autism
PDD-NOS	- Pervasive Developmental Disorder Not Otherwise Specified
SCQ	- Social Communication Questionnaire
SRS	- Social Responsiveness Scale
CAST	- Childhood Autism Screening Test
ASSQ	- Autism Spectrum Screening Questionnaire
ADI-R	- Autism Diagnostic Interview - Revised
ADOS	- Autism Diagnostic Observation Schedule
ADOS-G	- Autism Diagnostic Observation Schedule-Generic
DISCO	- Diagnostic Interview for Social and Communication Disorders
APA	- American Psychological Association
ICD	- International Classification of Disease
DSM	- Diagnostic and Statistics Manual of Mental Disorders
ROC	- Receiver Operating Curve
AUC	- Area Under the Curve
PPV	- Positive Predictive Value
NPV	- Negative Predictive Value
Se	- Sensitivity
Sp	- Specificity

ABSTRACT

Objectives

The European Autism Information Systems Project (Posada & Ramirez, 2008) highlighted the lack of systematic and reliable data on the prevalence of autism spectrum disorders in Europe. The EAIS project designed a protocol for the study of ASD prevalence at European level to facilitate a common format for screening and diagnosing children across the EU. This is the first study to operationalise the screening phase of the protocol and validate the use of a screening instrument the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as a primary screener for ASDs among national school children.

Methods

A study booklet completed by the parents of eligible children aged 6-11 years was returned to the teacher for collection by the study team. There were (n = 7,951) primary school children screened males 54% (n =4,268) females 46% (n = 3,683), special education school children (n = 189) males 66% (n = 125) females 34% (n = 64), in three regions: Galway, Waterford and Cork. Participation rates for parents of eligible children were 69% (n=5,457) for national schools, 36% (n=69) for special education schools.

Results

The distribution of SCQ total scores for the national school sample were strongly skewed towards lower scores 4.65 ± 4.75, range 0-36. The majority of children (92%) scored in the normal range (0 to11) (n = 5002), moderate (12-14) (n = 225) 4%, high ($\geq$15) score range 4% (n = 230). An optimal cut off score ($\geq$13) differentiated ASD from other diagnosis sensitivity 0.90, specificity 0.81, positive predictive value 0.43, and negative predictive value 0.98. Test re test reliability mean interval: 15 months, Pearson's r of 0.77, df = 499, $p < 0.001$.

Conclusions

The feasibility of screening children for ASDs with the EAIS protocol, using the SCQ in a non-clinical setting of Irish primary and special schools was demonstrated.

CHAPTER 1
THE IRISH AUTISM PREVALENCE STUDY
CONTEXT & DEVELOPMENT

The current DSM-IV TR criteria for autism require impairments in the following three categories: qualitative impairment in social interaction, qualitative impairment in communication, and restrictive, repetitive and stereotypic patterns of behaviours and activities (APA, 2000). In the last decade, the prevalence of autism has increased dramatically (Manning *et al.,* 2013). In 2012 The Centre for Disease Control (CDC) estimate the prevalence of autism spectrum disorders in the US to affect 1 in 88 children for 14 Autism and Developmental Disabilities Monitoring (ADDM) network sites for the 2008 surveillance year. The ADDM network acknowledge that ‘‘the extent to which these increases reflect better case ascertainment as a result of increases in awareness and access to services or true increases in evidence of ASD symptoms is not known.’’
To my knowledge only two studies have been undertaken to estimate the prevalence of autism spectrum disorders in Ireland which were undertaken by Van DenHeuvel *et al.,* (2007) and McCarthy *et al.,* (1984). In the former study Van DenHeuvel *et al.,* (2007) screened preschool children as part of an 18 month developmental assessment in two regions in the Republic of Ireland Cork and Kerry using the Checklist for Autism in Toddlers CHAT reported an overall prevalence of clinically diagnosed autism 33.1 per 10,000 (95% CI: 13.3 to 68.0).

There have been developments in the provision of legislation for the parents of children with special education needs to access diagnostic and education services in Ireland, for example implementation of the Epsen Act (2004) relates to the provision of education services for children with intellectual disabilities and the Disabilities Act (2005) provides a legal framework for the provision of health and education assessment and services to persons with a disability to support them in their school, social, community and home settings (Parsons *et al.,* 2009).

Given that there have been no previous studies undertaken to estimate the prevalence of autism spectrum disorders in Ireland among school aged children the current study was part funded by an Irish charity, Irish Autism Action.

This prevalence data is essential for the provision of current and future diagnostic and education services. Children diagnosed during primary school are likely to have had difficulties for some time but without a clear context for these difficulties, while children already diagnosed with ASDs will typically be in a variety of school placements by the age of 6 years of age. The range of placements include mainstream class with/without support, special ASD class, special school either ASD specific or Intellectual Disability (ID) specific (Health Services Executive ,2012).

A limited number of population based studies have been performed to screen children for autism spectrum disorder primarily because of the costs associated with undertaking these studies. Methodological difficulties include the fact that there is no medical test that can determine in an absolute way whether or not a child has autism. diagnostic criteria described in terms of descriptions of behaviour, as a result professionals may differ in the way they apply the criteria, even if they are using one of the standard systems, for example DSM-IV-R (APA, 2000) or ICD-10 (WHO, 1992). Furthermore diagnostic terms tend to be used in different ways so case findings methods may vary, for example studies that assess and diagnose every "at risk" individual in the sample to be assessed will find higher numbers than studies that rely on retrospective case finding methods (European Commission, 2005).
In February 2005, the European Commission for Health and Consumer Protection Directorate-General highlighted the requirement for EU policy relating to the screening and diagnosis of autism spectrum disorders. In response, a network of professionals and stakeholders concerned with ASD, the European Autism Alliance (EAA) drew up the European Autism Information System Project (EAIS) supported by DG Sanco EU funding.

The EAIS Project (2006-08) (Posada & Ramirez *et al.,* 2008) developed a proposal which included the following objectives:

- Improving the knowledge of base of the ASD services relating to the public health, educational system, social services and/or parents' organizations existing in those countries where the EAIS project is being carried out and to find out the pathway that people with an ASD need to follow to access services.

- Obtaining information relating to data access difficulties in ASD prevalence studies (data sources) when these studies are developed at European countries.

The current study is the first to operationalise the screening phase of the protocol and validate the use of a screening instrument the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as a primary screener for ASDs among a population of national school children. Implementation of the protocol will be explained in detail in Chapter 3 – Methods.

My role in the study was to managing the project, liaising and getting feedback from the study team at regular intervals providing progress reports.

The main takes I undertook on the study were as follows:

- Develop a study booklet for completion by parents of children eligible to participate in the study.
- Undertake pilot studies to determine the effectives of the current EAIS protocol.
- Identify three representative study regions in the Republic of Ireland for screening children within a school setting.
- Having identified the potential study regions invite primary schools in these regions to participate in the study.
- Undertake fieldwork in two of the regions (Galway, Waterford) and co-ordinate fieldwork in Cork. Two part time fieldworks were employed to undertake the first screening phase in Cork City.
- On completion of fieldwork in the schools, co-ordinate the data entry quality control process which was undertaken by an external organisation which specializes undertaking large scale surveys.
- Identify children who obtained moderate and high scores on the SCQ, making contact with the parent who originally completed the study booklet to recomplete the screener for the study child.
- Confirm consent to access to psychological assessments for children identified with a previously diagnosed developmental disorder, including ASDs.
- Identify a final sample of children who require referral for ADOS/ADI-R assessment liaising with the study team.
- To co-ordinate a validation study of children who obtained SCQ scores in the normal range. Part time support staff was temperately employed to assist in undertaking this phase.

The current study has made a number of contributions to the field of autism research in terms of proving evidence for the implementation of the EPAP protocol for screening children for autism spectrum disorders within a school setting, and the validation of SCQ as a first level screening instrument for use in community settings among a population of school going children.

CHAPTER 2
LITERATURE REVIEW

1.0 Introduction

In this chapter in Section 1 an overview of disability legislation in Ireland will be briefly discussed relating to assessment services for children suspected of having an underling autism spectrum disorder, intervention services for with an ASD diagnosis will be outlined. Current source of epidemiological data relating to the prevalence of intellectual disabilities in Ireland available through the Central Statistics Office and Health Research Board will are reviewed in this section. Section 2 provides an brief historical context to the diagnosis of autism spectrum disorders and autism phenotypes as classified under the Diagnostic and Statistics Manual (DSM) and American Psychological Association (APA) criteria.

The psychometric properties of screening instruments are discussed in Section 3, in Section 4 methodological issues relevant to screening for ASDs provided by health surveillance and national screening committees in the UK will be outlined. Study methodology and findings from epidemiological studies undertaken in education settings to screen children for ASDs will is provided in this section. In Section 5 the findings from studies that used the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as a screening instrument in clinical settings will be explored, the findings of studies which used alternative ASD screeners developed for school aged children outlined in Section 6.

In the final section in this chapter, Section 7 factors relating to the diagnosis of autism spectrum disorders are explored which include difficulties encountered by clinicians diagnosing the disorder relating to co-morbid medical conditions. Evaluations that should be included as part of multidisciplinary assessment and the gold standard instruments, the Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) and the Autism Diagnostic Observation Schedule – Generic (ADOS-G: Lord *et al.,* 2000) will also be discussed in this section.

Chapter 2 - Section 1.0

Disability Legislation in Ireland Relevant to Autism

1.1 Introduction

A detailed study of the number of children with developmental difficulties who require health assessment and intervention services has not been undertaken in Ireland (Health Services Executive, 2008). In this section a brief overview of current disability legislation and the provision of services for children on the autism spectrum (ASDs) in Ireland will be reviewed.

1.2 Primary Schools

In recent years, an increase is evident in the number of children with a diagnosis of autism spectrum disorder attending mainstream provision in Ireland n = 2,571 in 2008-9 compared with (1,675 in 2006/7). The number of schools offering autism specific classes has expanded rapidly up from 87 classes, 2001 to 339, 2008. Overall, this suggests that more schools across the range of provision are enrolling children with a diagnosis of autism spectrum disorder, addressing these children needs is increasingly requiring specialists for example in terms of providing autism support specific classes (Parsons, Guldberg, MacLeod *et al.,* 2009).

1.3 National Disability Steering Group

The National Disability Steering Group (2008) was established to identify a number of core principles for the delivery of health services for individuals in Ireland with a diagnosis of ASD (Health Services Executive, 2012).

The remit was to work in an advisory capacity to the HSE to implement multidisciplinary services for children 5- 18 years of age, in accordance with the Disability Act (2005) and EPSEN Act (2004).

Some of the key recommendations were as follows:

- Establish referral pathways for all children who require assessment and intervention used across health and education settings.
- Children should receive assessment and intervention services at primary care level, referred to specialist services as necessary.
- School aged interdisciplinary teams should provide specialist services for children with all disabilities in each health and social care network.

- A referral forum for children with complex needs (i.e. 4% of the total child population) should be established by primary care and network care teams, Child and Adolescent Mental Health Services (CAMHS) and agencies, providing sub specialist services, to co-ordinate referrals to appropriate services.
- Specialist medical services should be co-ordinated at national level and accessed regionally. These include neurology, ENT/specialist audiology, genetics and inherited metabolic disorders.

The Education for Persons with Special Education Needs EPSEN Act (2004) provides for supporting rights of children to an assessment, to an individual education plan, and to an independent appeals process. It fits into a legislative framework which, inter alia, includes the Education Act, 1998, the Education (Welfare) Act, 2000, the Equal Status Act, (2000) and the Disability Act, 2005 under the overall umbrella of the Constitution as well as various international agreements and human rights provisions.

The EPSEN Act (2004) provides for the right to an assessment. Assessment can be accessed in one of three ways:
(i) Through the school principal Section 3(2) – where the principal is of the opinion that a child is not benefiting from the education programme in the school, he/she is obliged to take measures to meet the educational needs of the child.
(ii) Section 4(1) of the Act obliges the Health Board (now the HSE) to cause an assessment to be carried out in respect of a child who is not a student. Section 4(2) of the Act places a similar obligation on the NCSE.
(iii) The Act allows, where parents are concerned that their children may have a special educational need, to request that an assessment be carried out. It also provides the parents with the right to appeal the refusal by the NCSE/HSE to carry out an assessment.
Assessments are to be completed within three months and establish the right to an education plan resulting in an individual education plan (IEP). The purpose of the education plan is to guide the delivery of services, to encourage effective teaching and learning, to promote access to a full curriculum, to monitor progress and to review the attainment of specific goals.

The Disability Act (2005) places legal obligations on the HSE regarding assessment of need and service statements for all individuals with a disability and on the autism spectrum.

The terms of the act indicate that an assessment of need should commence within three months. It is expected that most children with diagnosed disabilities and complex needs will already have received an assessment of need under this act with a service statement and annual reviews of their needs prior to transferring to early intervention services.

Transition to appropriate school aged services should be managed in co-operation with early intervention teams (Health Services Executive, 2009). Services for children with ASD in Ireland are currently poorly coordinated and developed in many areas of the Country. Where autism specific teams are in place, services are delivered in separate silos without any regard for national protocol or framework policy to guide the delivery of specialist services (Health Services Executive, 2012).

The National Disability Steering Group (2008) made key recommendations:

- The allocation of specific multidisciplinary teams with a designated co-ordinator in each community area.
- Pointed to the need for comprehensive information packs for parents regarding services available and specific support for siblings.
- Recognised a need for staff training and education in the area of ASD.
- Establish a database to capture the numbers of children with ASD to plan future services.
- Advocated for early screening, diagnosis and timely interventions.

They recommended the delivery and development of ASD services to include Primary Care Teams (PCT) specialist Disability or Child and Adolescent Mental Health Service (CAMHS) and sub specialist autism specific services at health and social care network level. These services would facilitate individuals to have access to appropriate multidisciplinary assessment. ASD specific teams are required to work in conjunction with primary care and network teams within identified catchment areas. Teams should comprise a mix of psychology, speech and language therapy, occupational therapy, psychiatry, social work, dietician, clinical nurse specialist, and administrative support (Health Services Executive, 2009).

The National Reference Group on Multidisciplinary Disciplinary Services for children 5 – 18 years of age reported that a comprehensive information system was needed to ascertain the prevalence of childhood disabilities in Ireland and plan services. In the absence of an Irish study, estimates of the prevalence of the more common childhood disabilities are based on a variety of sources Health Services Executive (2009) which will be discussed in this chapter.

1.4 Sources of Epidemiological Intellectual Disability Data in Ireland

1.4.1 Health Research Board

The Health Research Board manages two national service-planning databases for people with disabilities on behalf of the Department of Health and Children. They ensure that valid and reliable date are available for analysis, dissemination and service planning:

- National Intellectual Disability Database (NIDD), established in 1995
- National Physical and Sensory Disability Database (NPSDD), established in 2002

The disability databases aims to provide comprehensive and accurate information for decision making in relation to the planning of specialised health and personal social services for people with intellectual, physical or sensory disabilities.

The National Intellectual Disability Database (NIDD) provides information on specialised health services currently used or needed by people with intellectual disability. The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need.

The following information is provided:

- Demographic profile of people with intellectual disability.
- Specialised health services received by people with intellectual disability.
- Waiting times for specialised health services.

The National Physical and Sensory Disability Database (NPSDD) provide information on specialised health services utilised by people with physical/sensory disabilities. The database is managed by the HRB on behalf of the Department of Health and Children. The Database assists in informing the regional and national planning of these services by providing information on current service use and future service need.

As not every individual in Ireland who has a physical/sensory or speech & language disability is availing of, or requiring a specialised health and personal social service and as the registration on to the database is voluntary, the NPSDD cannot provide any definitive epidemiological statement on the number of people with a particular type of disability. Therefore the database may not cover a proportion of people living in Ireland who have a physical or sensory disability.

1.4.2 Irish Epidemiological Studies

Fitzgerald, Matthews, Birkbeck and O'Connor (1997) examined diagnostic, prevalence, psychosocial and service issues in relation to persons with autism in the Eastern Health Board area in the period 1990-1992. This study has since been updated and reprinted (Fitzgerald, Matthews, Birkbeck 2002). The first study was published in 1997 and found 272 (5 per 10,000) persons in the age-range 0-25 years who met diagnostic criteria for autistic disorder using the Autistic Disorders Diagnostic Checklist (Wing, 1987). DSM-I11-R and ICD-10 criteria gave a prevalence rate of 4-5 per 10,000.

More recently a study by VanDenHeuvel., Fitzgerald M., Perry IJ (2007) assessed the feasibility of administering the Checklist for Autism in Toddlers (CHAT) at the 18-month developmental check, to estimate the prevalence of screening positive for autism at the first and second administrations of the CHAT and estimate the prevalence of diagnosed cases of autism. The CHAT was administered to 2117 infants the overall prevalence of clinically diagnosed autism following this screening exercise was 33.1 per 10,000 (95% CI: 13.3 to 68.0).

1.4.3 The Irish Census

The Census of Population has been the primary source of information on numbers of people with disabilities in Ireland. In 2006 questions on disability were broadened to include learning difficulties, intellectual disabilities, psychological and emotional conditions, this resulted in a rise in the prevalence rate for all developmental disorders from 2.1% of children in 2002 to 3.2% in 2006, a more comparable estimate was provided by the National Disability Survey (2008) which reported that 11% of children aged 0-17 years reported having a disability. Working estimates of prevalence for disabilities by category based on the total population of 5-18s in the census of 2006 estimated the prevalence of autism spectrum disorder at 4,730, 0.6%.

The Census (2011) showed that 57,709 people or 1.3% of the population suffered from an intellectual disability. The greatest incidence by far was amongst 10-14 year old males, with almost 4,000 affected in this age group more than double that of females 1,900 in the same age group.

1.4.4 Special Education Administrative System (SEAS)

The National Council for Special Education (NCSE) estimates ~18% of children 5-18 years of age have special education needs (Implementation Report: Plan for the Phased Implementation of the EPSEN Act 2004 lbid). For planning purposes, the Health Services Executive (HSE) uses an estimate of (4%) of children who have complex ongoing needs for health supports with (10%) having occasional needs for health intervention. Currently, interdisciplinary services for children with disabilities, are delivered through the HSE and or a number of funded agencies, under (Section 38, 39 of the Health Act 2004).

The Special Education Administrative System (SEAS) is a purpose designed computer system aimed at providing an efficient and effective special education administration system used by the National Council for Special Education (NCSE). It enables SENOs and NCSE staff to manage and maintain school, teaching hours, SNA posts, assistive technology and transport (Banks & McCoy, 2008).

The 2010 SEAS figures reported that 2953, 17.76% children in receipt of resource teaching hours had a diagnosis of autism spectrum disorder enrolled in primary school pupils. The system also provides statistics on the number of pupils at primary level allocated a special education needs assistant SNA. The largest categories are students with Emotional Behavioural Disorders 2352, 24%, autism spectrum disorders 2369, 24%, and physical disabilities 1519, 15% (Banks & McCoy, 2011).

1.5 Discussion

There remains a lack of cohesion between the Health Services Executive, Dept. of Education and Skills (DES) and National Council for Special Education (NCSE) to develop a model to identify and meet the health and education needs of children with autism spectrum disorder. Services for children are poorly coordinated and developed in many areas of the country. Where autism specific teams are in place services are delivered in separate silos without regard for national protocols or framework policy to guide the delivery of specialised services (Health Services Executive, 2012). At present assessments are conducted in a variety of settings, both private and public through the Child and Adolescent Mental Health Services (CAMHS) and lack of clear guidelines resulting in varying standards in the quality of assessments performed (Health Services Executive, 2012).

Epidemiological data provided by Fitzgerald *et al.,* (1997) among 0-25 year olds is no longer relevant, 4-5 per 10,000 recent prevalence estimates provided by Kim et al., (2012) estimate prevalence of autism spectrum disorder 165 per 10,000 (95% CI: 111 – 218).
Existing Irish data sources are not practical for the purposes of estimating the prevalence of autism spectrum disorders. The Health Research Board Intellectual Disability Database (NIDD) records intellectual disability in terms of level of functioning rather than by type of disability. Data is only provided by services on a voluntary basis.

Questions in the Irish Census 2011 were not related specifically to disability categories. They were derived from two questions the first a seven part question which asks about the existence of long lasting conditions e.g. blindness, deafness / hearing impairment, basic physical activities, intellectual disability, learning memory or concentrating. The second is a four part question which rates difficulty performing various activities related to self care, going outside the home, and employment.
The National Council for Special Education (SEAS) database is still in development, ~ 4 per cent of the primary and post-primary school population students with special education needs have additional resource teaching hours at primary and post-primary. However, NCSE data only provide information on children who have been assessed and have supports in schools that is those who are allocated resources by the NCSE (Banks & McCoy, 2011).

Chapter 2 – Section 2.0

Autism Spectrum Disorders

2.1 Introduction

In this section autism spectrum subtypes will be broadly discussed: that is Autistic Disorder, Asperger syndrome, PDD-NOS, Rett's Disorder, and Childhood Disintegrative Disorder, in relation to the current diagnosis criteria according to DSM IV (APA, 1994) and ICD-10. (WHO, 1993). Particular emphasis will be placed on the higher functioning autism phenotypes. In the discussion section problems with the current diagnostic classification systems will be outlined, and the implications of the proposed amendments in DSM V for diagnosing autism spectrum disorders will be outlined.

The *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev. [DSM-IV-TR]; (American Psychiatric Association, 2000) lists five developmental disorders:

- Autistic disorder.
- Asperger's disorder.
- Rett's disorder.
- Childhood Disintegrative Disorder.
- Pervasive Developmental Disorder, not otherwise specified (PDD-NOS).

2.2 Autistic Disorder

Leo Kanner (1943) first described "early infantile autism". Kanner and Eisenberg (1956) provided the first formal set of diagnostic criteria for the diagnosis of autism. The criteria focused on two dimensions of the condition; a profound lack of affective content and repetitive, ritualistic behaviour. Autism is now viewed as a complex developmental disorder characterised by severe impairments in reciprocal social interaction, communication and patterns of repetitive or stereotyped behaviour (American Psychiatric Association, 2000; Kanner, 1943).

The diagnosis of autism requires disturbances in each of three domains: 1) social relatedness, 2) communication and play, 3) restricted interests and activities. By definition the onset is by age 3 (Volkmar, Klin, Siegel, Szatmari, *et al.,* 1994).

In the social domain, symptoms include:

- Impaired use of non verbal behaviours (e.g. eye contact, facial expression, gestures) to regulate social interaction.
- Failure to develop age appropriate peer relationships.
- Little seeking to share enjoyment or interests with other people.
- Limited social emotional reciprocity.

Communication deficits include:

- Delay in or absence of spoken language.
- Difficulty with conversational reciprocity.
- Idiosyncratic or repetitive language.
- Imagination and pretend play deficits.

Deficits in the behaviours and interests domain include:

- Unusual interests.
- Inflexible adherence to non functional routines.
- Stereotyped body movements.
- Preoccupation with parts or sensory qualities of objects.

The term 'Autism/tic Spectrum Disorders' reflects the notion that these conditions are related and may be difficult to differentiate with current diagnostic tools (New York State Dept. of Health Early Intervention Programme, 1999; Lord *et al.,* 1998).
For a child to meet criteria DSM-IV-R (APA, 2000) criteria for autistic disorder, he/she must demonstrate at least 6 of 12 symptoms, with at least 2 coming from the social domain, and 1 each from the communication and restricted repetitive interests categories.

The most classic picture of autism is presented by preschool children who may exhibit marked lack of interest in others (Stone, 1997). However, marked resistance to change, restricted interests, and stereotyped movements may develop or become more noticeable after age 3 years (Lord *et al*, 1996).

Younger children with autism may exhibit attachment to specific objects, but unlike typical transitional objects in normally developing children, the attachment objects of children with autism are more likely to be hard rather than soft, and the actual objects may be less critical than the class of object (Volkmar., Cook., Pomeroy *et al.,* 1999).

Although awareness of the importance of early diagnosis has increased among paediatricians and primary care providers, delays in case definition of autism remain relatively common (Stone, 1997). Common presenting complaints from parents at two years include: concern about the child's language, inconsistencies about responsiveness, or concerns that the child might be deaf (Volkmar., Cook., Pomeroy *et al.,* 1999).

There is variability in the age at which children present features essential for the diagnosis of autism (Lord & Pickles, 1996). Predictors of ultimate outcome include the presence of communicative by speech age 5 and overall cognitive ability (IQ) (Stone, 1997). By school age, greater differential social responsiveness usually develops and communication skills increase. Problems in dealing with change and transitions and with various self-stimulatory behaviours may become more prominent (Loveland & Tunali-Kotoski, 1997).
In adolescence a small number of autistic individuals can achieve marked developmental gains, while another subgroup can behaviourally deteriorate. An increased risk for the development of seizures in noted in adolescence (Mesibov & Handlan, 1997).

2.3 Asperger Syndrome

Hans Asperger (1944) first described Asperger syndrome, with case histories of four children (all male) each with five common clinical features: social deficits, insistence on sameness, non-verbal language deficits, stereotypes and lack of humour. He believed that the main handicap of the disorder was social in nature and was not due to delays or deficits in language or intellect (Eisenmajer *et al.,* 1996).

The condition received relatively little attention in the English literature (Volkmar, Klin, Shultz *et al.,* 1996) until Lorna Wing (1981) introduced Asperger's "autistic psychopathy" to the English language and renamed the cluster of characteristics as "Asperger Syndrome". Asperger Syndrome has been described in the literature under various headings which included: Schizoid Disorder (Ssuchareewa & Wolff, 1996), Schizotypal Personality Disorder of Childhood (Nagy & Szatmari, 1986) and Non Verbal Learning Disability

Stein et al, 2004) and Atypical Development (Mahler & Furer, 1972). The first set of formal diagnostic criteria for Asperger Syndrome were formulated by Gillberg and Gillberg (1989) followed by ICD-10 (WHO, 1992) & DSM-IV (APA, 1994).

Wing. (1981) presented several different features, affecting children in the first two years of life which included lack of normal interest in:

- Pleasure in people around them.
- Deceased quality and quantity of babbling.
- Significant decrease in shared interests.
- Significant decrease in the wish to communicate either verbally or non-verbally.
- Delayed in speech acquisition.
- Lack of imaginative play or play that is confined to one or two rigid patterns.

Gillberg. (1989) presented six diagnostic criteria:

- Social impairments
- Narrow interests.
- Repetitive routines.
- Speech and language peculiarities & non-verbal communication problems.
- Motor clumsiness.

Gillberg's criteria are believed to be the closest to Asperger's original characteristics (Schnur, 2005). The introduction of Asperger Syndrome in DSM-IV / ICD-10 was prompted by the recognition that autism is a clinically heterogeneous disorder.
In the field trials conducted as part of DSM IV and ICD-10 cases of a clinical diagnosis of Asperger syndrome were noted to differ from autism in terms of verbal performance IQ profile and increased rates of circumscribed interests, and differentiated from PDD-NOS in terms of the severity of social difficulties (Volkmar, Klin, Siegal, 1994).

When Asperger syndrome was introduced in the current diagnostic classification systems it was placed alongside autism as a pervasive developmental disorder, sharing the same criteria as autism but differing in terms of its apparently normal cognitive functioning and language development.

On the basis of the onset rule, and the number of communicative impairments that are present in autism but absent in Asperger syndrome, autism automatically takes priority in the diagnostic hierarchy (the precedence rule) (Woodbury-Smith, Volkmar, 2009).
A diagnosis of Asperger syndrome requires communicative use of single words demonstrated by age 2 and meaningful phrase speech by age 3. Autistic disorder must be ruled out before a diagnosis is justified. The diagnosis of autism always takes precedence over that of Asperger syndrome (APA, 2000). Consensus has not been achieved on the validity of the distinction between higher functioning forms of autism and Asperger syndrome (Howlin, 2003; Macintosh & Dissanayake, 2004).

Asperger's syndrome has been referred to as autism without mental retardation, high functioning autism or milder forms of autism marked by higher cognitive or linguistic abilities (Klin, McPartland, Volkmar 2005). Despite the DSM-IV diagnostic implications that there are no language impairments, language in children with Asperger syndrome is not typical or normal. Children with Asperger syndrome share many of the same features as children with autism but do not have a history of language delay and usually have average or above average intellectual abilities (Klin *et al.,* 2005; Sunil, 2006).

Socially children with Asperger syndrome may not appear to be as withdrawn as those with autism, but tend to approach others in inappropriate or eccentric ways (Klin *et al.,* 2005). Children with Asperger syndromes befriend others, but inherent in their friendships are difficulties related to awkwardness and perceived insensitivity on the part of others. They participate in conversation, but have a tendency to only discuss topics they are interested in and fail to banter back and forth in a typical two way conversation.
They may have flat emotionless speech, often obsessed with particular topics, ask repetitive questions and display concrete and literal thinking (Inglese & Elder, 2009).

2.4 High Functioning Autism

Although not listed as an official DSM IV TR (APA, 1994) diagnosis classification high functioning autism has typically been used to describe individuals with autistic disorder who have an IQ above the mentally retarded range (IQ $\geq$ 70) (Howlin, 2003) but demonstrate a clear delay or impairment of language acquisition at an early stage in development (Noterdaeme, Wriedt, Hohne, 2010).

The differentiation between higher functioning autism phenotypes is controversial (Szatmari, Bryson, Duku *et al.*, 2009). There has been limited agreement on the best diagnostic criteria for Asperger syndrome (Woodbury-Smith et al., 2005; Klin *et al.,* 2005; Kopra *et al.,* 2008). Furthermore it is difficult to compare AS/HFA as the criteria for Asperger Syndrome have been modified by different authors (Mahler & Furer, 1972; Nagy & Szatmari, 1986; Gillberg & Gillberg, 1989; Ssuchareewa & Wolff, 1996; WHO, 1992; APA, 1994; Volkmar., Klin, et *al.,* 2000).

On the basis of accumulated research evidence there are few qualitative distinctions between higher functioning autism and Asperger disorder with most behavioural features and biological indices shared or overlapping to some degree (Macintosh & Dissanayake, 2004). It appears that identified differences may be more pronounced during the first year of life than during middle or later in childhood (Eisenmajer *et al.,* 1996; Gilchrist *et al.,* 2001; Howlin, 2003; Szatmari *et al.,* 1995).

Ozonoff *et al.* (2000) found that Asperger disorder was associated with greater social competence relative to high functioning autism at 4-5 yrs of age but this difference was no longer apparent at 6-21 yrs of age. On the basis of clinical descriptions, the criteria as presented in DSM IV (APA, 1994) regarding social impairments in Autistic disorder and Asperger syndrome are identical.

Cognitive profiles have been analysed in subjects with Asperger syndrome and High Functioning Autism. High verbal intelligence on the performance scale of the Wechsler intelligence test and earlier language development are more likely to be found among persons with Asperger syndrome than those with high functioning autism, but the results are inconsistent (Ghaziuddin *et al.,* 2004; Gilchrist *et al.,* 2001; Koyama et al., 2007; Ozonoff *et al.,* 2000., 1991; Szatmari *et al.,* 1989).

Eisenmajer *et al.,* (1998) found that early language delay predicted the extent of autistic psychopathology, motor delay, and receptive language skills when children were young but not at an older age. Manjiviona & Prior (1995) compared level of motor impairment in Asperger syndrome and high functioning autism, subjects in both groups demonstrated motor problems. Saulnier & Klin (2007) found higher verbal IQ scores and less symptomatology in individuals with Asperger's than those with high functioning autism. Impairments were comparable on the Vineland scores, highlighting adaptive deficits in both groups.
More recently Noterdaeme *et al.,* (2010) found that subjects with Asperger's had significantly higher scores on full and verbal scale IQ then subjects with high functioning autism, differences on performance IQ were not significant. Subjects with high functioning autism had clearly more expressive and receptive language problems.

2.5 Pervasive Developmental Disorder Otherwise Not Specified (PDD-NOS)

The most frequently diagnosed subtype is "PDD-NOS", yet it is the least well characterised (Fombonne, 2005). The DSM IV TR (APA, 2000) does not provide clear guidelines how many symptoms should be endorsed for a diagnosis of this phenotype (Snow & Lecavalier, 2011). PDD-NOS is a label generally assigned by clinicians for children who experience difficulties in at least two of the three autism related symptom clusters but do not meet criteria for any of the other pervasive developmental disorders (APA, 2000).
The same list of DSM-IV-R (APA, 2000) symptoms is used to diagnose PDD-NOS but only one difficulty within the reciprocal social interaction domain, and one symptom from either the communication deficits or repetitive, restricted behaviour domains are required (APA, 2000). This is a very heterogeneous category (Walker *et al.,* 2004). The diagnosis is often misused, with substantial proportions of children carrying this label either meeting the full criteria for autism or not meeting the criteria (Buitelaar, van der Gaag, Klin & Volkmar, 1999).

Studies on diagnostic agreement suggest that expert clinicians reach higher agreement when discriminating Autism Spectrum Disorders from other disorders than when attempting to distinguish between subtypes, especially when attempting to differentiate PDD-NOS from other phenotypes (Mohoney *et al.,* 1998; Volkmar *et al.,* 1994).
Level of functioning has been shown to moderate the presentation of core autistic symptoms (Buitelaar *et al.,* 1999) and associated features such as gender (Sponheim & Skjeldal, 1998) behaviour problems (Lecavalier, 2006) medical conditions (Amiet *et al.,* 2008) and course of the disorder (Shattuck et al., 2007). Recent studies have found IQ is the most consistent indicator of differences between sub types (Witwer & Lecavalier, 2008).

Snow & Lecavalier (2011) examined behaviour and emotional problems among three groups of children with PDD-NOS, Autistic Disorder and Asperger syndrome. For both preschool and school aged children the most commonly reported co-morbid problems were affective, anxiety, and attention problems. These findings are contrary to previous studies which have reported group differences in tics, compulsions, oppositional behaviour, social withdrawal, depression symptoms, anxiety and psychotic symptoms (Gadow *et al.,* 2004, 2005; Pearson *et al.,* 2006; Wesibrot *et al.,* 2005). The authors argued that without controlling for level of functioning it is difficult to know whether sub group differences were true differences between groups or artefacts of differences in IQ.

2.6 Retts Syndrome (RS)

Andreas Rett (1966) first described this progressive genetic neurodevelopmental disorder which is one of the most common causes of mental retardation in females. Rett's syndrome (RS) was only internationally recognized after Hagberg (1983) described 35 cases. RS is characterized by apparently normal development for the first 6–18 months of life, followed by a period of regression in language and motor skills.

Characteristics of the disorder include loss of purposeful hand use replaced with repetitive stereotyped hand movements, social withdrawal, communication dysfunction, loss of acquired speech and cognitive impairment (Matijevic, Knezevic *et al.,* 2009).
Other features of the disorder include: panic-like attacks, respiratory dysfunctions (episodic apnea and/or hyperpnea), impairment of sleeping patterns, progressive kyphosis or scoliosis, decreased somatic growth (Williamson & Christodoulou, 2006).

There is a range of severity of RS, and some individuals have been reported to retain and develop language skills (Kerr et al., 2001; Smeets *et al.,* 2005). Milder cases are more likely to be associated with a different type and location of genetic mutation on the MECP2 gene than those with classic RS (Kerr et al., 2001; Smeets *et al.,* 2005; Neul *et al.,* 2008). Estimates of rates of ASD in RS range from ~25% - 40%, but may be up to ~ 97% of those with the preserved speech variant of the syndrome. The overlap between RS and ASD was previously considered to be robust in classifying the disorder as a PDD alongside autism according to ICD-10 (WHO, 1992). However, the DSM-IV (APA, 1994) diagnostic criteria now considered inappropriate because of distinct differences in phenomenology between the two disorders (Moss & Howlin, 2009).

2.7 Childhood Disintegrative Disorder (CDD)

Theodor Heller (1908) described six children who suffered severe regression in social and communication skills after apparently normal development in the first 3-4 years of life (Heller, 1908). Childhood Disintegrative Disorder (CDD) is rare, and most of the literature is described in case reports (Volkmar, 1992). The condition is also known as: Dementia Infantilise, Heller's syndrome, Progressive Disintegrative Psychosis (Corbett *et al.,* 1977). Disintegrative Psychosis and Pervasive Disintegrative Disorder (WHO, 1993) and Childhood Disintegrative Disorder (APA, 1994). The major distinction between RS and CDD is that the former mainly occurs in girls, and regression onset occurs at an earlier age in RS (Volkmar, 1992).

CDD differs from classic autism in the mode of presentation, with a prolonged period of normal development, followed by a marked loss of skills. There is no known consistent aetiology, and extensive medical investigations have generally not revealed evidence of abnormality (Volkmar *et al.,* 1997; Militerni *et al.,* 1997; Malhotra *&* Singh 1993; Mouridsen et al, 2000). The majority of reported cases function at an IQ level commensurate with severe to profound mental retardation (Mouridsen *et al.,* 1998; Malhotra *et al.,* 1993; Volkmar *et al.,* 1989; Burd *et al.,* 1998).

2.8 Discussion

The clinical characterisation of Asperger syndrome has been defined differently by clinicians from Han's Asperger's (1944) original definition, who reported among his cases, an early onset of language acquisition and at least average intelligence. Wing (1981; 2000) postulated the possibility of delayed onset of language acquisition and a mild form of mental retardation. Tantam (1988) defined a good command of language, abnormal non-verbal expression and social isolation despite the wish for social contact. Tantam did not take language acquisition and cognition into consideration. Gillberg criterion was closer to Asperger's original contribution. Klin *et al.,* (2005) defined isolated interests, early language acquisition, and unusual sensory interests.

The developments of current diagnostic classification systems have alleviated inconsistencies to certain extent. However, there are still some major problems, in particular the diagnostic definitions have been criticised as been to narrow in view of the precedence rule and "onset criteria" to the extent that assigning children a diagnosis of Asperger syndrome is unlikely adhering rigorously to diagnostic guidelines (Eisenmajer *et al.,* 1996; Mayes *et al.,* 2001; Miller & Ozonoff, 1997).

Using onset as inclusion/exclusion criteria whereby individuals are considered for a diagnosis of Asperger syndrome only in the absence of early speech delay or impairments in self-help skills, adaptive behaviour or curiosity about the environment has several disadvantages. A fundamental concern is that this criterion tends to tilt the diagnosis towards autism on the basis of vague developmental phenomena, such as the development of words or phrases. Other criticisms of the current classification systems have related to the failure to include additional features described by Asperger, for example the presence of motor clumsiness was noted by Asperger (1944) and subsequent clinicians who described core characteristics of the disorder (Gillberg & Gillberg, 1989; Tantam, 1988; Wing, 1981) including pragmatic aspects of language rather than semantics or syntax (Woodbury-Smith, Klin, Volkmar, 2005). Excessive emphasis may have been given to Asperger's assertion that early developmental histories tend to be normal. Whilst Asperger did suggest that the early histories of his cases were normal, subsequent analysis of his cases has found at 25% of the patients he saw and diagnosed had evidence of delays in language and / or cognitive development (Hippler & Klicpera, 2003).

The use of retrospective recall of language millstones as a means of differentiating Asperger syndrome and high functioning autism has been criticised partly due to potential parental recall bias and that the criterion are overly inclusive (Klin *et al.,* 2005). Bennett *et al.,* (2008) reported that waiting until the child is 6 years of age was more predictive of later outcome as compared to the clinical standard of assessing language milestones at 2-3 years of age as defined by the DSM IV or the assessment of structural language at 4-6 years of age. Bennett *et al.,* (2008) argued that given the role of assigning diagnostic labels is to highlight and predict diagnostic outcomes. The assessment of structural language impairments at a later age may be more useful for subcategorizing children with autism spectrum disorder phenotypes.

There are structural difficulties in terms of language impairments between autistic disorder (autism) and Asperger syndrome. Wing (1981) described the speech of patients with Asperger syndrome as pedantic and lengthy, Gillberg (1989) as superficially prefect expressive language which is formal and pedantic, and having odd prosody and peculiar voice characteristics. These characteristics are fundamentally different from the type of language and communication impairments described in autism in which language is delayed, echolalic, idiosyncratic, and repetitive (Woodbury-Smith, Klin, Volkmar, 2005).

Both the DSM IV (APA, 1994) and DSM IV R (APA, 2000) state that Pervasive Developmental Disorders (PDDs) cannot be diagnosed in conjunction other commonly occurring conditions such as: ADHD, stereotyped motor disorder, schizophrenia, obsessive compulsive disorder and anxiety disorders (Wing *et al.,* 2011). Despite this, clinicians often diagnosis the two conditions as co-occurring (Posey *et al.,* 2007).

The clinical characteristics of OCD, according to DSM IV are very similar to that of "autistic psychopathy" as described by Asperger (1944). The co-occurrences of anxiety disorders including OCD have been demonstrated to be greater than chance levels in children with high functioning autism (Sukholdolsky *et al.,* 2008; White *et al.,* 2009). Child and Adolescent Psychiatric Working Party have reported all sub divisions will be removed in DSM IV leaving a single category of autism spectrum disorders (Rutter, 2011) Removal of subtypes of ASD is controversial (Ghaziuddin. 2010) partly because patients and their families may fear the loss of medical insurance benefits (Wing *et al.,* 2011).

Although not clearly spelled out the Working Party is that the overall undivided ASD category should be used for a period when children with Rett's syndrome show features of autism. Rett's syndrome was included as a sub category of ASD in DSM IV partly because the neurological section of ICD-10 did not make any mention of the syndrome. As far as DSM V is concerned, the difficulty is that, unlike ICD-10 the condition does not form part of an overall medical classification. Childhood Disintegrative disorder has been subjected to limited research it is not known whether the disorder constitutes an unusual variant of autism or something quite different (Rutter, 2011).

Finally the validity of the distinction between autistic subtypes is currently unclear (Witwer & Lecavalier, 2008). Researchers have argued for a classification system that takes level of functioning into consideration (Beglinger & Smith. 2001; Frith. 2001; Szatmari, 2000). This could enhance the validity of a classification system as it is a good indicator of group differences (Snow & Lecavalier. 2011). Revisions to current classification systems will ultimately be judged on whether they result in greater validity of diagnostic categories. Modifications that achieve this goal are those that promote identification of the disorder, improve clinical decision making, and promote progress in understanding of the aetiology (Kraemer *et al.,* 2007).

Chapter 2 - Section 3.0

Psychometric Properties of Screening Instruments for Childhood Development

3.1 Purpose of Screening for Childhood Developmental Disorders

Universal early screening is a critical aspect to providing early school based prevention and intervention services for students at risk of or with academic, behavioural or emotional difficulties. Systemic approaches have been developed for providing support to individuals at risk of such difficulties (Glover & Albers, 2007).

Although a screening instrument may be appropriate for the specific administration context and purpose for which it has been selected, it is not useful unless it can reliably and accurately predict performance and behaviour for the population of interest. Guidelines for an instruments technical adequacy are described in *The Standards for Education and Psychological Testing* (AERA *et al.,* 1999). These guidelines provide information about criteria for proper development, evaluation and use of educational and psychological tests (Glover & Albers, 2007).

Specifically an instrument should be:

- Appropriately standardised for use with a target population.
- Consistent in its measurement.
- Accurate in its identification of individuals at risk.

3.2 Rating Scales for Autism Spectrum Disorder

The advantages of rating scales include the ease and efficiency of administration scoring, and low cost. Many rating scales are short allowing for a large number of individuals to be assessed with limited resources. They allow the rater to consider a wide range of behaviours over a broad time period, across a variety of different settings (Williams & Brayne, 2006). Many screening instruments have been developed in a rating scale format, designed to be completed by caregivers and quickly scored by professionals. Rating scales are not without limitations, as they invite the rater to make subjective judgements/inferences, and many only apply to a limited range of age or level of functioning (Norris & Lecavalier, 2010).

Although all measures strive for accuracy, this consideration is especially important for screening instruments. If a child is misclassified during the screening process, valuable time for intervention can be lost. It's imperative to have accurate screening instruments for autism spectrum disorders to facilitate early diagnosis and intervention few screens have been subject to rigorous evaluation in population based samples (Norris & Lecavalier, 2010). The following instruments will be briefly discussed. Their validity and reliability will be examined in *Section 6.0 – Review of Screening Instruments for School Aged Children*. The Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) has been submitted to rigorous evaluation to discriminate individuals with autism spectrum disorders from other disorders (e.g. ID, ADHD, language disorders). Studies have been performed by independent research teams (Charman *et al.,* 2007; Chandler *et al.,* 2007; Corsello *et al., 2*007; Johnson *et al.,* 2011).

The Social Responsiveness Scale (SRS: Constantino & Gruber, 2005) has received wide attention due to the availability of population norms (Constantino & Gruber, 2005) its flexible format useable for teachers and parents alike and excellent psychometric properties (Constantino & Gruber, 2005; Constantino, Hudziak & Todd, 2003a; Constantino *et al.,* 2006, 2007; Duvall *et al.,* 2007; Pine *et al.,* 2006). Neither the Social Responsiveness Scale (SRS: Constantino & Gruber *et al.,* 2005) or the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) screening instruments have been used as screening instruments in epidemiological studies, specifically to screen children from autism spectrum disorders. Their sensitivity, specificity, and optimal cut off remain to be established in the general population (Fombonne *et al.,* 2012).

3.3 Technical Characteristics of Screening Instruments

3.3.1 Reliability

According to classical measurement theory, reliability can be expressed in the following equation: Obtained score = true score ± error score. The true score can never be known because no measure is perfect. The error score cannot be known either; however, the amount of both random and systematic error can often be controlled for. Stability reliability is tested when the attributes under study are not expected to change. Equivalence reliability indicates whether all items reliably measure the same attributes and if participants scores on similar on equivalent measures (DeVon, Block, Moyle-Wright *et al.,* 2007).

3.3.2 Test re - Test Reliability

Test re test reliability is estimated by administering the same test to the same group of respondents at different times. The correlation between the two scores, and often between individuals questions, indicate the stability of the instrument. Time intervals between the original test and retest are somewhat controversial. Two weeks to one month is the generally accepted time interval for retesting (Waltz *et al.,* 2005). The time interval should be long enough that respondents do not remember their original responses, but not long enough for their knowledge of the material to have changed, as a rule, the longer the time, the lower the reliability (Trochim, 2005).

3.3.3 Equivalence Reliability

Cronbach's alpha coefficient is the most frequently used statistic to measure internal consistency reliability. Internal consistency indicates how well items on a tool fit together conceptually. Coefficient alpha is the only reliability index that can be performed with one test administration, requiring less effort than split-half, alternative form, or retest methods (Ferketich, 1990). Higher alpha values can be achieved by adding items, provided that they are correlated (DeVellis, 2003; Nunnally & Bernstein, 1994). If items are not correlated, the value of alpha is reduced. Inflated alpha values are achieved when computed for an entire scale, i.e. composed of two or more sub scales. In this case, coefficient alpha should be computed for each sub scale rather than the entire scale (Nunnally & Bernstein, 1994), coefficient alpha 0.70 is acceptable for new scales (DeVellis, 2003). Several authors have recommended alpha should be minimally 0.90, with an ideal value of 0.95 (Bland & Altman, 1997; Nunnally & Bernstein, 1994; Polit & Beck, 2004).

3.3.4 Alternative Form Reliability

Unlike retest reliability, alternative form reliability pertains to different versions of an instrument to determine reliability scores. Alternative forms can prevent participants from using knowledge gained from the first test in answering questions during subsequent administrations (DeVon, Block, Moyle-Wright *et al.,* 2007). Also known as parallel forms (DeVellis, 2003; Waltz *et al.,* 2005), alternative forms reliability pertains to scores from two tests, each with different items from an item "pool" to test the same concepts. Both versions of the instrument must measure the same phenomena and have scores with approximately equal means, variances, and alpha coefficients. Some authors have suggested correlations of at least 0.80 between tests (Brinks & Wood, 1998).

Generating sufficient items for two forms of a test might prove difficult or impossible. Therefore alternative forms reliability is not frequently used in clinical research, and is more commonly employed in education studies in which pools of items are larger (DeVon, Block, Moyle-Wright *et al.,* 2007).

4.0 Validity

In an attempt to establish a unified approach to validity, the American Psychological Association (1999) published standards that integrate emerging concepts. These standards readily translate to clinical practice and research providing a comprehensive approach for assessing the validity of results derived from psychometric instruments (Cook D.A, Beckman T.J, 2006). Because the validity of an instrument's scores hinge on the construct, a clear definition of the intended construct is the first step in any validity evaluation. Validity is not a property of an instrument, but of the instrument's scores and their interpretations (Messick, 1989; American Education Research Association, 1999).

Validity has traditionally been separated into three discrete types: content, construct, and criterion validity (APA, 1966). While accruing evidence one should specifically consider two threats to validity: inadequate sampling of the contact domain (construct under-representation) and factors exerting non random influence on scores (sampling bias or construct irrelevant evidence) (Messick 1995; Dowling & Haladyna, 2004).

4.1 Content Validity

An instrument has content validity if the items that comprise the measure, represent the entire domain of skills and behaviours the test was developed to measure (Aiken, 1985). Content validity concerns the degree to which the items on a scale are appropriate, broad enough, and thorough enough to capture the true attributes to be measured. Content validity reflects a value judgement, and often comes from a panel of experts (Fullerton, 1993) asked to review the potential scale items and validate that they are appropriate indicators of the construct (Schultz & Whitney, 2005). The earliest stages of instrument development should include the largest pool of potential items possible, which can be reduced, based on content reviews (Netemeyer *et al.,* 2003).

4.2 Construct Validity

Construct validity is the degree to which an instrument measures the construct it is intended to measure (Cronbach & Meehl, 1955). It is supported if the instrument items are related to its operationally defined theory and concepts. For example, if an instrument is intended to measure autistic traits is contractually valid, if all items in the tool have the capacity to exclusively measure concepts that are theoretically and structurally related to autism. However, if the instrument also has the capacity to measure symptoms of closely related disorders i.e. Dyspraxia. The instrument might not have adequate construct validity to measure autistic traits. An instrument might be "construct valid" but not capable of measuring the intended construct (DeVon, Block, Moyle-Wright *et al.,* 2007).

The factors listed below should be taken into consideration in the evaluation of construct validity (Cook D.A & Beckman T.J, 2006). They are often presented as a detailed description of steps to ensure the items adequately represent the construct (Hayes *et al.,* 1995):

- Construct definition.
- Instruments intended purpose.
- Procedure for selecting and developing the items.
- Wording of the individual items and the qualifications of the item writers and reviewers.

The construct validity of an instrument can be demonstrated using: contrasted groups, hypothesis testing, factor analysis, and the Multi Trait-Multi Method (MT-MM) approach. In the contrasted group approach, two groups known to be high and low in the construct being measured are sampled. The mean scores of the two groups should differ significantly in the expected direction if the instrument is valid. Hypothesis testing is based on a theoretical framework and indicates the expected direction of scores on the measure. Construct validity is supported if the scores reflect the framework as hypothesized. Factor analysis is a statistical method commonly used during instrument development to analyse relationships among large numbers of variables. A factor is a combination of test items that are believed to belong together (DeVon, Block, Moyle-Wright *et al.,* 2007).

Using factor analysis related items define parts of the construct are grouped together - unrelated items do not define the construct and should be deleted from the instrument (Munro, 2005). Exploratory factor analysis (EFA) helps investigators identify the various factors that define the construct. EFA is used to identify the greatest variance in scores with the smaller number of factors, expressed statistically as an eigenvalue (>1.0). Confirmatory factor analysis (CFA) generally follows EFA and includes theoretical knowledge to further test the construct validity of the tool. CFA validates the extent to which the statistical model fits the actual data (Waltz, Strickland, & Lenz, 2005).

The multi trait – multi method (MT-MM) approach can be used whenever two or more constructs are been measured with two or more methodologies. A matrix shows the degree of correlation and the relationship between traits. Different measures of the same construct should be correlated highly with each other (converge) and different constructs should show low correlation with each other (discriminate) (DeVon, Block, Moyle-Wright *et al.,* 2007).

4.3 Criterion-Related Validity

Criterion related validity refers to the extent that a particular measure corresponds with another measure of interest. Where two or more measures can be shown to measure the same outcome, then either could be used. Under these circumstances the choice of measure could be based on issues such as ease of use or cost effectiveness. Likewise, if it is demonstrated that two instruments measure much the same construct, but each adds an additional distinct and important piece of information, then both instruments may be used together (Fullerton, 1993, DeVon Block, Moyle-Wright *et al.,* 2007).

4.4 Predictive Validity

Predictive validity is perhaps the most important indicator of screening instruments tests accuracy. For a screening instrument to be effective it must be able to distinguish between those who will and will not have subsequent performance of behavioural difficulties. Four indices are useful in evaluating the predictive validity of a screening instrument: Sensitivity; specificity; positive predictive value, and negative predictive value (Glover & Albers, 2007).

Four mutually exclusive categories arise where a test:

1. Correctly identifies someone with the disease as positive, this is labelled is true-positive.
2. Incorrectly identifies someone with the disease as negative, this is labelled is false-negative.
3. Correctly identifies someone without the disease as negative, this is labelled true-negative.
4. Incorrectly identifies someone without the disease as positive, this is labelled false-positive (over referrals).

The ability of a test to measure what it claims to measure is stated in terms of sensitivity and specificity. Sensitivity refers to the proportion of individuals with the disease whom the test correctly identifies. Specificity is the proportion of individuals without the disease whom the screening test will correctly identify as not having the condition (Rydz *et al.,* 2005).
A Receiver Operator Characteristic (ROC) is a plot of the sensitivity/specificity pairs resulting from continuously varying the decision threshold over the entire range of the results observed. The ROC plot provides a comprehensive picture of the ability of a test to make the distinction being examined over all decision thresholds. On the y axis is sensitivity, or the true positive fraction [defined as (number of true positive test results)/(number of true positive + number of false negative test results)].

It is calculated solely from the affected group. On the x axis is the false positive fraction, or 1 – specificity defined as [(number of false positive results)/(number of true negative + number of false positive results)] (Zweig & Campbell, 1993). A decision threshold must be chosen for a test to be used for screening purposes. There is no need to choose any particular decision threshold for test accuracy; in fact it is undesirable to do so, because assessing performance at a single point may result in misleading impressions about the test performance or erroneous comparisons between tests (Turner, 1978; Robertson, Zweig, Van Steirteghem, 1983).

Because the true/false positive fractions are calculated entirely separately, by using the test results from two different subgroups, the ROC plot is independent of the prevalence of the disease in the sample. Each plot on the ROC plot represents a sensitivity/specificity pair corresponding to a particular decision threshold. A test with perfect discrimination (no overlap between the two distributions of results) has a ROC plot that passes through the upper left corner where the true positive fraction is (1.0) or 100% (perfect sensitivity) and a false positive fraction (0) (perfect specificity). Quantitatively, the closer the plot is to the upper left hand corner the higher the overall accuracy of the test (Zweig & Campbell, 1993).

Positive predictive value (PPV) defines the proportion of individuals testing positive (failing a screening test) who actually have the condition. The negative predictive value (NPV) is the proportion of individuals who test negative who do have the condition. Both values are related to the prevalence of a disorder in the general population, a lower prevalence of a condition will reduce negative and positive predictive values (Rydz *et al.,* 2005).
In evaluating the adequacy of a screening instrument it is helpful to consider the practical implications associated with indices of predictive validity. Four indices can be useful in determining a screening instruments adequacy, positive predictive value (PPV) and negative predictive value (NPV) sensitivity and specificity, sensitivity and PPV are often considered the most important. Lower the positive predictive value increases the chance that an instrument is over identifying individuals at risk of a disorder (Glover & Albers, 2007). This can result in over referrals for autism specific assessments (ADI-R/ADOS-G) over use of programming resources, and increased stress among family members or support personnel (Algozzine & Ysseldyke, 1986; Mercer, Algozzine,, & Trifiletti, 1988).

The screening instruments sensitivity is also important – a low sensitivity value may indicate the instrument is under identifying children at risk who are not receiving relevant supports and services. When the consequences associated with under identification are great, it may be useful to compromise precision (e.g. a high positive predictive value or specificity) for inclusion (sensitivity). For a multi-gate screening assessment programme, sensitivity at the first gate is critical for insuring that no children who are potentially at risk are overlooked, increasing positive predictive value is expected for subsequent gates (Glover & Albers, 2007).

Other characteristics of a screening instrument include, the appropriateness of the measured construct and content, timing and frequency of administration, suitability of the informant, and representatives of the normative sample, may contribute to its predictive validity (Bennett et al., 1998; Bordingnon & Lam, 2004; Fletcher & Satz, 1984; Gredler, 2000b).

5.0 Usability

Although a screening instrument may be appropriate and technically sound, it is not likely to be useful for identifying individuals at risk unless the test is perceived to be practical to administer, and useable within a specific context. The following considerations are important in evaluating the usability of a screening instrument (Glover & Albers, 2006):

- The cost of a screening instrument must not out weight the benefits associated with its administration (Flanagan, Bierman, & Kam, 2003).
- It is important to consider whether the sensitivity and positive predictive value of the instrument are appropriate with respect to available resources.
- Consideration should be given to the required infrastructure for collecting, managing and interpreting screening assessment data.
- Appropriate accommodations should be made available for the target population, for scoring and interpreting instructions i.e. English is a second language.
- Information afforded from the screening instruments completion should be useful to stakeholders, and ideally result in improved treatment utility (i.e. helpful in guiding treatment decisions (Hayes, Nelson, & Jarrett, 1987).
- Screening without intervention planning and delivery is not only wasteful, but can negatively impact those who are labelled as a result of the assessment process (Meier, 1975).

6.0 Discussion

A clear understanding of the concepts validity and reliability in psychometric assessment is essential for the development of reliable and valid rating scales. Validity concerns the degree to which scores reflect the intended underlying construct, and refer to the interpretation of results rather than the instrument itself. Validity is best viewed as a carefully structured argument in which evidence is assembled to support or refute proposed interpretations of results. Reproducible (reliable) results are necessary, but not sufficient, for valid inferences to be drawn (Cook & Beckman, 2006).

With respect to the use of Receiver Operating Characteristic (ROC) curves in practice, choosing an optimal threshold value is practicable only for continuous data. All operating points on the curve correspond to correlated realistic threshold values (Van Erkel *et al.,* 1998) - the smooth ROC curve is falsely suggestive of continuity for ordinal texts results (Dwyer, 1996).

A similar problem occurs when a categorical rating scale of disease probability is used in generating the ROC curve. The actual threshold value in clinical practice is unclear and cannot be related to scientifically observe operating points. Because only part of the ROC curve represents clinically relevant combinations of sensitivity and specificity, comparing the ROC curves in the relevant sensitivity and specificity ranges is preferable to comparing the total area under the curve (Van Erkel *et al.,* 1998).

Determining the optimal operating point involves both clinical and financial issues (Van Erkel *et al.,* 1998). Ideally such decisions should be made by linking the constructed ROC curve to explicit cost effective decision analysis (Halpern, Albert, Krieger et al., 1996; DeNeef & Kent., 1993). These issues have implications for health care applications such as rater agreement in radiology, (Kundel *et al.,* 2003) the development of illness severity scales, (Knaus *et al.,* 1991; Fine *et al.,* 1997) and clinical pathways (Marrie *et al.,* 2000).

Chapter 2 - Section 4.0

Screening for Autism Spectrum Disorders among School Age Children

4.1 Introduction

Screening is the prospective identification of unrecognised disorders by the application of specific tests and examinations. Surveillance refers to the ongoing and systematic collection of data relevant to the identification of a disorder overtime by an integrated health system (Baird., Charman., & Baron-Cohen *et al.,* 2000). Screening offers the unique opportunity to alert primary care physicians and other health care providers to cases in the population that require further attention. Effective screening must be efficient in terms of utilisation of health care resources and cost (Robins, 2008).

Population screening for disorders is warranted (Robins, 2008) when:

- The cost of not detecting the disease is high.
- Diagnostic criteria are identified.
- Intervention is available.
- Early intervention is more effective than later intervention.
- An appropriate screening test is available.

Early identification is important for reducing the delay in referral to a specialist who can diagnose Autism Spectrum Disorder (Koegel *et al.,* 2005). This should reduce the burden of the disorder on individuals and society at large (Robins, 2008). Although the validity of early diagnosis has been questioned, longitudinal studies have demonstrated that diagnoses made around the second birthday are stable when children are re-evaluated at 4 years of age (Charman et al. 2005; Cox *et al,* 1999; Freeman & Cronin, 2002; Lord, 1995; Lord *et al.,* 2006; Moore & Goodson, 2003; Stone *et al., 1*999) emphasising the need for effective screening procedures (Robins, 2008).

Young children who are delayed in the acquisition of skills (e.g. joint attention, pre verbal and social communication) are at risk of persistent problems in social and communication development even if they do not go on to meet diagnostic criteria for autism or a related Pervasive Developmental Disorder (PDD). This broader group of children may benefit from intervention for the prevention of secondary problems (Baird *et al.,* 2001).

Although it is common for children with autistic disorder to be identified during the preschool period through the local health care system, too many children are only identified when they start primary school (Yeargin-Allsopp, 2003). Analysis of US special education data by Newschaffer *et al.,* (2005) indicated that the proportion of children receiving an autism special education classification continues to increase through the elementary school period. Hamilton *et al.* (2006) reported that most children who would qualify for early intervention in the US under federal law are not identified before school entry. Shattuck *et al.,* (2009) found that the median age of identification to be 5.7 years of age.

4.2 Developmental Surveillance for Autism Spectrum Disorders

Developmental surveillance is an on-going process of monitoring the status of a child by gathering information regarding the child's development and behaviour from multiple sources, including skilful observation of the child's behaviour and elicitation of concerns from parents and relevant professionals (Squires *et al.,* 1996; Dworkin & Glascoe, 1997). Both the American Academy of Predicates and the British Joint Working Party on Child Health Services recommend developmental surveillance as an effective means to identify children with delay. Public health care physicians play a critical role in identifying children with developmental delay at a young age. They are in regular contact with the child from birth through to adolescents and therefore can monitor development longitudinally, allowing for better understanding of the child's immediate developmental trajectory (Gilbridge, 1995). Developmental gains will be greatest if a child participates in intervention services as early as possible, a concept iterated in public laws in the USA, Individuals with Disabilities Education Act (IDEA) - Amendments of 1997, which mandates early identification and intervention for children with developmental disabilities (Majnemer,1998).

Although developmental surveillance can be a powerful identification tool for young children prior to school entry, fully implementing this strategy in the context of medical practice is difficult for a verity of reasons (Rydz *et al.,* 2005):

- Time constraints do not allow the practitioner to implement surveillance, and may be omitted altogether when dealing with more acute health problems.
- It is not likely to work well for infants receiving infrequent care by different practitioners at different stages in a child's development (Dutton, 1979).
- The efficacy of the strategy is dependent on the practitioner's knowledge and experience of autism and related disorders.

4.3 Developmental Screening for Autism Spectrum Disorders

The Working Party on Child Health Surveillance (UK) (Hall, 1996) identified several difficulties applying Wilson & Junger (1968) criteria, designed to evaluate screening programmes, for identifying developmental disorders, such as autism spectrum disorder:

The main difficulties included:

- Lack of clarity over case definition.
- The unpredictability of natural history in developmental conditions.
- Lack of evidence gathered on the effectiveness of interventions.

As a result of these difficulties the Working Party on Child Health Surveillance stated that screening for autism could not be recommended at the time (Hall & Elliman, 2003).
There is uncertainty about defining 'caseness' for autism spectrum disorders, and other developmental disabilities i.e. language disorders, current psychometric tests tend to have low sensitivity and specificity (Law, Boyle, Harris, 2000; 1998). This is particularly the case for screening tests that have attempted to identify a specific condition, rather than general developmental delay for the identification of relatively rare disorders.

With respect to the application of instruments developed to screen for specific disorders, even when sensitivity & specificity remain constant, the positive predictive value (PPV) (the proportion of children with a positive screen result who go onto have the disorder) is lower the rarer the disorder is within a population (Clark & Harrington, 1999).
With respect to parent completed screening tests, there is evidence that the use of screening instruments in combination with asking parents about their concerns improves the efficacy of a screening instrument. The number and types of concerns a parent has about the child's behaviour and development determine whether using a screening instrument within a clinical setting is effective (Glascoe, 1997; 1999). The weakest area of screening for Autism Spectrum Disorder is the availability of data supporting the appropriateness of specific screening instruments which require further study before appropriate instruments can be recommended for use as part of a national screening programme (Mawle & Griffiths, 2006).
The Medical Research Council review (MRC, 2001) highlighted the need for complete and active case ascertainment in epidemiological studies for autism spectrum disorders.

The review highlighted difficulties of active case ascertainment in a research setting and noted the lack of a suitable screening test. They did not systematically address whether screening might be desirable as a public health service, but raised concerns regarding population screening (Williams & Brayne, 2006).

These concerns included:

- The risk of missing children with developmental difficulties.
- Raising unnecessary worries among the parents of unaffected children i.e. false negatives.
- Ethical implications of diagnosing individuals where there were no previous concerns.

The National Autism Plan (NAP: LeCouteur *et al.,* 2003) provided clinical best practice guidelines for the screening and assessment of autism in the UK, they recommended:

- Autism can be detected through increased awareness among parents and health professionals.
- Screening tests may be valuable if used as secondary screens to screen children for specific disorders who have established developmental problems.

The UK National Screening Committee (Gray, 2004) stressed there is insufficient evidence available from the current literature to judge issues relating to the development and implementation of a national screening programme with regards to the condition, availability of appropriate screening tests and treatments.

The Committee but forward that once these building blocks are in place other criteria need to be addressed:

- The level of severity of the disorder that would require justification through a screening programme.
- The benefits of a screening programme must be shown to out weight anxiety resulting from a false positive.
- The Stigma of a true positive.
- Difficulty of getting a diagnostic assessment following a false negative.

The National Autism Plan (NAP: LeCouteur *et al.,* 2003) and the Scottish Needs Assessment (PHIS, 2001) identified delays and deficiencies in the current methods of identifying and diagnosing children with autism spectrum disorder in the United Kingdom:

They made the following recommendations:

- Training professionals in 'altering' signals of possible autism spectrum disorder at preschool and at school age.
- There should be regular opportunities during early childhood (8-12 mths, 2-3 yrs, and 4-5 yrs) to discuss a child's development with parents as part of surveillance to detect and respond rapidly to any developmental concerns.
- Multi-agency autism specific assessment should be available in local areas.

The UK National Screening Committee for autism spectrum disorders argued that if a screening programme was to become an option, it would be essential to conduct a randomized controlled trial of the whole screening programme from the outset. The UK National Screening Committee (Gray, 2004) highlighted a number of methodological problems and proposed a number of recommendations relevant to the development and implementation of a national screening programme.

Methodological issues included:

- Debates over case definition need to be resolved, including exploring the boundaries of the condition, improving definition of sub groups, and description of change in presentation of the disorder with increased age (Medical Research Council, 2001).
- A better understanding of the variation in autism prevalence is required for accurate planning of resources.
- A more complete description of the earlier stages and natural history of autism spectrum disorders are required through longitudinal studies so primary and secondary interventions can be fully explored.

Recommendations included:

- As molecular genetic studies lead to a greater understanding of the genetic basis of autism, careful consideration of new primary prevention options and means of identifying autism are required.
- The provision of evidence from high quality, randomized controlled trials that screening programmes are effective in reducing morbidity, and that the tests accurately measures the risks of autism spectrum disorder.
- The opportunity cost of the screening programme should be economically balanced in relation to expenditure on medical care as a whole (i.e. value for money).
- Public pressure for widening the eligibility criteria for reducing the screening interval, and for increasing sensitivity of the testing process, should be anticipated. Decisions about these parameters should be scientifically justifiable to the public.

The National Screening Committee (Gray, 2004) also recommended the need for a fully validated effective screening test for use in the general population, and for diagnostic tests for use with very young children, those with learning disabilities, and more subtle forms.
Specific recommendations regarding test criteria included:

- The test should be acceptable to the population i.e. simple, safe, precise and validated.
- The distribution of test values in the targeted population should be known and a suitable cut off level defined and agreed.
- There should be a suitable policy on the future diagnostic investigation of individuals with a positive test result.

It is important to take into consideration that disorders that are behaviourally defined will not have the same level of agreement as biologically defined disorders, but this should not be an obstacle to screening. It is unlikely that instruments with perfect sensitivity and specificity will be developed for disorders like ASD that are behaviourally defined.
There will always be a trade-off between false positives (reduce positive predictive value and specificity) and false negatives (reduce sensitivity). It would be a tremendous clinical disservice to assume that screening could not be recommended until research supporting specific screening instruments and procedures are unequivocal (Robins, 2008).

4.4 Development of a Model Process for Screening in Education Settings

The need to define autism specific screening and assessment methods so that children within the public school system can receive more symptom specific targeted intervention is not a novel idea (Teal & Wiebe, 1986).

Filipek *et al.,* (2000) discussed *Practice Parameters for the Diagnosis and Evaluation of Autism* (p 439) which has implications for the development of school based ASD screening and educational diagnostic identification processes.

These parameters involve two levels:

- Developmental surveys of autism specific screening.
- Formal diagnostic evaluations of autism.

The 1st Level - *Routine Developmental Surveillance and Screening Specifically for Autism*, should be performed for all children and involves identifying:

- Children at risk of any type of atypical development
- Children specifically at risk of autism, mental retardation, other medical or neurodevelopment conditions.

Filipek suggested the screening process should include the following criteria:

- Standardised developmental screening tools of children's developmental skills in all domains.
- Discussion with parents regarding their possible concerns about the child, particularly in the areas of social, communication, and behavioural functioning.
- Direct observation of the child.
- Hearing evaluation.
- The use of autism specific screening instruments, when concerns have been identified in the areas of social, communication, and behaviour.

Routine developmental screening guidelines described by Filipek (1999): developmental millstones defined, recommended screening tools, red flags documents, and evidence-based recommendations were only relevant for screening and diagnosing autism spectrum disorders among infants and preschool children. These guidelines were not relevant to the identification of school going children with high functioning autism phenotypes.

2nd Level screening – *Diagnosis and Evaluation of Autism*, will be discussed in chapter 1.0 *Section 6.0 – Diagnosing Autism Spectrum Disorders*.

Literature available regarding the development and implementation of public school screening programmes for Autism Spectrum Disorder are sparse. The project Outreach (1980 – 1983) part of a US federal programme sought to provide consultative support to education staff, students and parents to co-ordinate a screening programme with local Child Study Units to conduct in service training. The project successfully demonstrated the needs of autistic children could be adequately provided for within the public school system (Smith & Brees, 1983).

This model was developed for implementation within rural school districts. The Colorado Department of Education Autism Task Force held a workshop for local child finding team's responsible for identifying disabled children in the community, (0-5) years of age to clarify the role of teams in the identification of ASD. In two rural districts of Colorado (Montrose and Delta) limited expertise and resources were available for screening and identification of children with Autism Spectrum Disorders. An IDEA 97 grant project was developed to address the need for improved school-based ASD screening and evaluation services (Norland & Gabriels, 2004).

A screening and referral process was developed, to clarify the roles and responsibilities of professionals in the identification and intervention of students believed to potentially manifest an Autism Spectrum Disorder. Red flag documents (based on Filipek *et al.,* 1999 criteria) were developed for per school children and a separate document for older students who demonstrated impairments in social, communication and/or behavioural functioning.

These documents were disseminated to school personnel for use in conjunction with existing documentation to identify concerns which included: checklists of potential areas of student difficulty in: attention, memory, peer relationships and academic work habit performance. The process was organised to provide both Level 1 and Level 2 evaluations as required, as described by Filipek *et al.,* (1999).

4.5 Methodological Issues Relevant to Screening for Autism Spectrum Disorders

A review by Charman *et al.,* (2002) highlighted the effectiveness of case finding methods for autism spectrum disorder screening, documenting sound methodological designs incorporated by previous studies and best practice guidelines for future studies.

Although the review was written ten years ago, the methodological issues outlined are relevant to epidemiological studies undertaken to the present date.

- The majority of studies have relied on a two stage procedure where an initial screening phase is followed by more intensive case ascertainment and diagnostic phase. More recent studies have used serial ascertainment methods over time to identify cases.
- Although the specificity of initial screens can be calculated, estimates of sensitivity have rarely been ascertained.
- Some prevalence studies have only included individuals within the special education system, by definition excluding cases of ASD within mainstream education. Cases can be missed when studies only ascertain cases already identified and diagnosed by clinical services.
- The size of the population sampled has been shown to systematically relate to the prevalence rates found, with higher rates been reported in smaller samples, presumably due to more intensive and comprehensive coverage, at a cost of wide confidence intervals (Fombonne, 1999).
- Multiphase detection mechanisms that target a whole population of medium size are likely to produce the most accurate prevalence estimates.

- Studies should adopt multiple case finding ascertainment methods, employ rigorous and standardised approaches to ascertainment and diagnosis in large, well defined and representative populations.
- An appropriate age of study is between 8-12 years of age. This is when autism symptoms have been well established and recognisable to most individuals across the IQ spectrum (Fombonne, 2002). The ADI-R/ADOS are more reliable for the identification of PDDs for children in this age range.

4.6 Determining the Prevalence of Autism Spectrum Disorders from Education Based Sources

4.6.1 Introduction

The majority of epidemiological studies undertaken from 2000 - 2011 which have screened school aged children 5-12 years of age for autism spectrum disorder, were primarily undertaken in Western European countries. A summary of these studies and characteristics is provided in the table at the end of this section. The majority of these studies identified cases retrospectively through education records, medical and community records. A limited number of studies screened children for autism spectrum disorder using standardised screening instruments.

4.6.2 Studies Identified

Retrospective case findings methods were used by (Bertrand *et al.,* 2001; Yeargin-Allsopp *et al.,* 2003; Tebruegge *et al.*, 2004; Williams *et al.,* 2008) to identify potential cases of autism spectrum disorder. These studies identified cases of autism spectrum disorder by expert review of educational and clinical evaluations abstracted using structured pro forma ICD-10 / DSM-IV diagnostic criteria. Webb et al., 2003 screened 11,692 children 7-11 years of age using an ICD-10 based screening questionnaire completed by teachers, children who obtained 2+ symptoms were rescreened using the ASSQ. Education records were reviewed to determine special education needs status, hospital and community abstracted by the authors to identify children on the autism spectrum.

Bertrand *et al.,* (2001) screened 17,792 children 3-10 yrs, Brink Township, New Jersey. Those suspected of autism spectrum disorder were identified from special education records, local clinicians, and community parent groups.

Children suspected of an ASD were referred for comprehensive multidisciplinary assessment which included developmental history, physical examination, cognitive and adaptive behavioural assessments. The gold standard ADOS and ADI-R were also included as part of the assessment process.

Baird *et al.,* (2006) screened an at risk cohort of children 56, 946, 9-10 yrs of age identified through special education needs registers. The study used a multiphase screening design which aimed to access the validity of ASD diagnosis made by local clinicians and to detect the rate of possible missed cases in a high risk sample with identified special education needs but not current ASD diagnosis. A rigorous screening and diagnostic procedure was implemented. Those identified exhibiting autistic traits were screened with the Social Communication Questionnaire (SCQ: Rutter *at al.,* 2003) positive screens were referred for multidisciplinary assessment which included ADOS, ADI-R, cognitive, language and occupational therapy assessment.

School going children were screened using first level standardised screening instruments in studies by Scott *et al.,* 2002; Ellefsen *et al.,* 2007; Baron-Cohen et al., 2009; Kim et al, 2011). Scott *et al.,* 2002 screened 43,472 children 4-11 yrs of age enrolled in mainstream schools. Parents of all eligible children completed the Childhood Autism Rating Scale (CAST: Scott *et al.,* 2002) followed by the SCQ. The CAST was also used an a first stage screen by Baron-Cohen *et al.,* (2009) among a population of 11,635 mainstream school children 5-9 yrs of age. In both of these studies screen positives were referred for ADOS / ADI-R assessments providing a research diagnosis of autism spectrum disorder.

Ellefsen *et al.,* (2007) screened children 7-16 years of age in the Faroe Islands. All children who attended mainstream schools were screened, except for those who attended special schools who were screened through SEN registers. Parents of children who were previously undiagnosed, but raised teachers suspicions requested permission to complete the Autism Spectrum Screening Questionnaire (ASSQ: Ehlers, Gillberg, Wing, 1999) for these children. Screen positives were referred for clinical evaluations which included physical examination, DISCO and WISC-R.

The ASSQ was also used as a first level screener in a South Korean study by Kim *et al.,* (2011), whereby positive screens were referred for assessment which included the ADOS, ADI-R, Leiter R or WISC III.

The only prevalence study to be undertaken in Portugal was by Oliveria *et al.,* (2007) who screened 343,718 children 6-9 years of age using a DSM-IV based checklist was completed by teachers. Those identified suspected to be at risk of an autism spectrum disorder were referred for assessment which included the Griffiths Developmental Scales, or WISC, CARS, and ADI-R. The psychometric properties of these first level screening instruments in addition to the Social Responsiveness Scale (SRS: Constantino & Gruber, 2005) will be discussed in the proceeding chapter.

4.6.3 Prevalence of Autism Spectrum Disorders

The highest prevalence rates of autism spectrum disorder among the studies reviewed were obtained by Kim *et al.,* (2011). This study targeted the entire elementary school population of a South Korean community, which included a two stage design using systematic multi informant screening. Screen positives were evaluated using standardised diagnostic instruments which included the ADOS / ADI-R and cognitive tests (Leiter R, WISC III).

The prevalence of ASDs was estimated to be 2.64% (95% CI: 1.91 – 3.37) with 1.89% (95% CI: 1.43 – 2.36) in the general population sample and 0.75% (95% CI: 0.58-0.93) in the high probability sample identified through special education registers. ASD characteristics differed between the two groups: the male to female ratios were 2.5:1 and 5.1:1 in the general population and high probability samples respectively, ratios of autistic disorders to other ASD subtypes 1:2.6 and 2.6:1. 29.8% of children IQ scores were in the border line to mild intellectual disability range in the high probability sample, and 11.6% in the general population sample. Baron-Cohen *et al.,* (2009) used a novel approach for estimating the prevalence of autism spectrum disorders. A statistical weighting procedure was used to estimate a prevalence rate of 157 per 10,000 (95% CI: 99-246). A rigorous multiphase screening and diagnostic procedure was applied in the study by Baird et al., (2006). The prevalence of childhood autism was 38.9 per 10,000 (95% CI: 29.9 – 47.8) other ASDs 77.2 per 10,000 (52.1 – 102.3) total prevalence for all ASDs 116.1 per 10,000 (95% CI: 90.4 – 141.8).

4.7 Discussion

Best practice guidelines underlying developmental surveillance and screening were discussed in this section. A number of issues were addressed by the Medical Research Council UK (MRC, 2001) which included the lack of a suitable test for use as part of a national screening programme for screening autism spectrum disorders, risk of missing children (false negatives), and the ethical implications of identifying and subsequently diagnosing children with autism spectrum disorders, where there were no previous parental concerns. The MRC also highlighted that the boundaries of autism phenotypes need to be more precisely defined with respect to the age of children screened for the development of more reliable and appropriate screening instruments.

The National Screening Committee UK (Gray, 2004) proposed that if a national screening programme was to be an option, it would be necessary to conduct a randomised control trial of the whole programme from the outset, to provide sufficient evidence that the programme was effective in reducing morbidity of the disorder and cost effective in relation to medical care expenditure at a national level. The alternative strategy to universal screening recommended by the committee was to increasing awareness of autism spectrum disorders among parents and health professionals, making existing screening tests available as secondary screens for children already identified disabilities with established developmental problems.

Robins (2008) argued that the National Screening Committee's criteria for a national screening programme were unrealistic. Pointing out that it is unlikely that a screening instrument can be developed with perfect sensitivity and specificity, a trade off will always be required in terms of false positives / negatives. He argued further it would a tremendous disservice to assume that screening should not be recommended until research supporting specific screening instruments and relevant screening protocols is unequivocal.

The major limitation of the studies discussed Williams *et al.,* (2008), Tebruegge *et al.,* (2004), Yeargin-Allsopp *et al.,* (2003) which screened school aged children for autism spectrum disorders, is that cases were identified using retrospective case finding methods, as such higher functioning children on the spectrum who had not come to the attention of education or health services at the time health when medical records were abstracted would not have been identified.

Prevalence estimates obtained from population based studies (Baird et al., 2006; Baron-Cohen *et al.,* 2009; Kim *et al.,* 2011) are more reliable than those based on searches of registered cases, which may lead to prevalence under estimation, particularly if good registers are not available (Lipkin , 1991). The studies reviewed which used first level screening instruments to identify potential cases of autism spectrum disorder had a number of limitations.

Firstly the highest prevalence estimates for autism spectrum disorder to date were reported by Kim et al., (2011). In this study the first level screening instrument Autism Spectrum Screening Questionnaire (ASSQ: Ehlers & Gillberg, 1993) used does not have established psychometrics as the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) or the Social Responsiveness Scale (SRS: Constantino & Gruber, 2005). Additional concerns regarding this study include the fact that there was a relatively small number of children referred for clinical assessment from a large population screened, and the disproportionate differences in the number of children recorded on the national disability register (<1.0%) relative to the questionable high prevalence rate reported 2.98% per 10,000. Baron-Cohen *et al.,* (2009) study response rates from parents were very low (26%) and cannot be regarded to be representative of the population screened as such the ratio of known to unknown cases was high 3:2. Parent and school reported diagnoses were not independently verified against education and medical records, which may have resulted in under or over reporting of cases of autism spectrum disorder. Among the studies reviewed the lowest rates of autism spectrum disorder were identified by Oliveria *et al.,* (2011) and Ellefsen *et al.,* (2007).

The authors were reliant on teachers (who may have varied considerably in teaching expertise, and the identification of children with social and communication difficulties) to identify children they suspected to be at risk of an ASD and complete DSM IV and ICD -10 based checklists (which are not standardised validated psychometric instruments) for the purposes of identifying children for assessment.

Although there were methodological difficulties relating to the identification of children in the screening in the studies performed by Ellefsen *et al.,* 2007, Oliveria *et al.,* 2007, and Kim et al., 2011 as discussed, and in the studies by Bertrand et al. 2001 cases were identified retrospectively through abstraction of clinical and education records, and Baird *et al.,* (2006) only children at risk of an ASD were screened.

Children identified through screening were referred for evaluations to confirm or refute a diagnosis on the autism spectrum. The studies undertaken by Scott *et al.,* 2002; Baron-Cohen et al., 2009 did not include cognitive and adaptive functioning assessments, both the ADOS & ADI-R were performed to provide a research diagnosis of autism spectrum disorder.

The objective of this section was to discuss the methodology issues relevant to screening school aged children for autism spectrum disorder. In the proceeding section the psychometric properties of screening instruments which were used as first level screeners in the studies reviewed will be discussed.

Chapter 2 - Section 5.0

The Social Communication Questionnaire

5.1 Introduction

The Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003), Lifetime Form was used as a first level screening instrument in the current Irish autism prevalence study. The screening instrument was included in a study booklet developed for completion by parents of all children 6-11 years of age. In this chapter comprehensive studies which screened school aged children will be reviewed 6+ years of age. In the proceeding chapter a number of other screening instruments specifically developed for autism screening will be reviewed.

5.1.1. Description of Scale

The Social Communication Questionnaire (SCQ: Rutter *et al*., 2003) (formally known as the - Autism Screening Questionnaire (ASQ: Berument *et al*., 1999) is a 40-item parent report questionnaire that asks about characteristic autistic behaviour. Each item is scored as 0 or 1. Total scores range from 0 to 39 (the first item is a language screening question that is not included in the total score). The questionnaire is based on the ADI-R (Lord et al, 1994) and has established validity for a diagnosis of autism (Berument *et al,* 1999). Nineteen items rate current behaviour and 20 items behaviour when the child was 4-5 years old - the recommended cut off score for autistic spectrum disorder is $\geq$ 15.

5.1.2 Distribution of Scores

The validation study of the SCQ was performed by Berument *et al*., (1999), participants (n = 200) included children and adults 4-40 years of age who had participated in previous clinical studies and had subsequently been diagnosed with autism and other neuro-developmental disorders. Disorders included autism (n = 83, 41%), atypical autism (n = 49, 24.50%) Asperger syndrome (n = 16, 8%) and other developmental disorders (n = 52, 26%) Fragile X syndromes, Rett's syndrome, conduct disorder, language delay, and mental retardation.

The male preponderance in autism 2.8:1 and other PDDs 6.7:1 was greater in the non PDD diagnostic group 1.7:1. In neither the autism and non the Non PDD group was there a statistically significant gender differences in ASQ scores in the autism (25.2 vs. 25.2) and the PDD group (11.1 vs. 11.3).

In the non-autistic group the mean SCQ score was lowest 8.38 in the sub group IQ > 70 and highest in the group with severe retardation (14.74) but did not vary by IQ within the PDD (including autism) group. The diagnostic differentiation within all IQ bands (including those with severe mental retardation) was highly significant.

Four steps were taken to assess the diagnostic validity of the instrument –

- Factor analysis was undertaken to determine whether the scale provided a differentiation that reflected the conceptualization of the three main domains of abnormality found in autism (reciprocal social interaction, communication, and repetitive stereotyped behaviour).
- Combination of individual items was assessed noting their correlation with the total score and extent to which they differentiated PDDs (including autism) from other diagnosis.
- Correlations between the ASQ and ADI were calculated.
- Receiver Operator Curves were applied to determine the degree to which the ASQ differentiated PDD from other diagnosis.

Corsello *et al*., (2007) examined the diagnostic discrimination of the SCQ among a sample of (n = 590) children and adolescents 2-16 years of age, who were conservative referrals and research participants within autism centres at two university based clinics specializing in the diagnosis of children with possible ASDs. Consensus best estimate diagnosis was provided by two examiners (child psychologist, child psychiatrist). Parents completed the SCQ for their child prior to diagnostic assessment. Clinicians were not aware of SCQ scores, but were knowledgeable of ADOS/ADI-R scores and classifications. The highest mean SCQ scores were obtained for children diagnosed with childhood autism 20.26 ± 6.82, other ASDs 18.66 ± 7.14 and children with other developmental disorders 11.86 ± 6.81.

Non-verbal and verbal IQs ranged from profound mental retardation to superior intelligence. There were significant differences in verbal and non-verbal IQs between the autism, PDD-NOS, NS (other disorders) groups, and were significant differences in gender with more males than females in the autism and PDD-NOS groups, than the NS group.

Charman *et al.,* (2007) collated data for a sub sample of the SNAP study (n = 119) children aged 9-13: IQ, severity of symptoms measured by the ADI-R and ADOS-G algorithm total scores. A total ICD-10 symptom count was systematically completed as part of the diagnostic review process, parent and teacher reports on emotional and behavioural problems; adaptive behaviour was assessed using the Vinland Adaptive Behaviour Scales (VABS: Sparrow et al., 1984).

The weighted mean was 73.4 (S.E =1.6) for the full sample, range 40-136, 56% of the children had IQ < 70. Scores for three screening instruments SCQ, SRS, and Childhood Behaviour Checklist (CCC: Bishop, 1998) were completed by parents before diagnostic assessments. Children subsequently diagnosed on the autism spectrum obtained the highest mean scores for all three screening instruments; mean scores for the SCQ are as follows: Childhood autism 25.8 (S.E = 0.5), other ASDs 19.2 (S.E = 1.1) and non ASDs 9.5 (S.E = 1.1).

Chandler *et al*., (2007) collected SCQ data from three samples: the Special Needs and Autism Project (SNAP) cohort of 9- to 10-year-old children with special educational needs with and without ASD and two similar but separate age groups of children from the general population n = 411 and n = 247. Diagnostic assessments were completed on a stratified subsample n = 255 of the special educational needs group. The mean SCQ score in the "at risk" sample was mean (SD) 15.2 (8.6), the sample screened nearly across the full range of possible scores (0-39) weighted mean (SD) scores. Children diagnosed with Childhood Autism 26.6 ± 4.4, and other ASDs 19.6 ± 6.6 mean SCQ scores were higher than for those with other developmental disorders 10.8 ± 6.1.

The distribution of scores was also reported among a school and general population based samples of children 9 to 10 years of age. Four percent of the school sample and 5% of the general population sample scored at the recommended cut off point, 11% and 7% had a diagnosis of autism spectrum disorder respectively.

Mulligan *et al.*, (2009) described the distribution of SCQ scores in a general population sample of school children aged 5 -13 years n = 240 of mixed gender. Mean SCQ scores were higher for males (4.46 ± 3.48) than females (3.99 ± 3.42) which were not statistically significant. Three children in the sample 1.8% scored $\geq$ 15.

5.1.3 Reliability

Corsello, Leventhal, Cook (2003) reported the alpha index of internal consistency for the SCQ among a clinical sample of children 2- 18 years of age with language (range: ∞ = 0.84-0.93) and without language (range: ∞ = 0.81-0.92) was uniform across the two groups, internal consistency increased with age. Bolte *et al*. (2008) reported that the German version demonstrated good internal consistency, alpha = 0.83 and temporal reliability measured over months to 2 yrs alpha = 0.76 among a small sample of children mean age 14 yrs, SD = 8.8 with ASD and other disorders.

5.1.4 Validity

Berument *et al*., (1999) reported the majority of SCQ items (n = 33, 85%) differentiated autism spectrum from other developmental disorders. Items which did not were related to abnormal language features these included: item 3 – stereotyped utterances, item 4 – inappropriate questions, item 5 pronoun reversal, item 6 – neologisms, item 17 self injury and item 14 unusual attachment to objects.

Each of these items had a relatively high frequency among non – PDD children but had substantial correlations with the total score, stereotyped utterances r= 0.64; inappropriate questions r = 0.53; pronoun reversal r = 0.45; neologisms r = 0.57. Two items self injury r = 0.37 and unusual attachment to objects r = 0.27 differentiated only at the 7% significance level, and showed modest correlations with the total score. Correlations between the ADI and ASQ were calculated for the total score and the ADI domain (social, communication, and repetitive behaviour) totals. Correlation coefficients were highly significant for all comparisons within and across domains and significant at the $p < 0.0001$ level.

Berument *et al*., (1999) reported that the discriminate validity of the ASQ was good at differentiating PDDs (including autism) from non – PDD conditions (including mental retardation). The ASQ similarly differentiated well between autism and mental retardation, autism and non PDD diagnosis other than mental retardation. There was significant differentiation between autism and other PDDs using a cut off score $\geq$ 20 and substantial overlap between phenotypes ($p < 0.001$). Examination of receiver operator curves for the total ASQ suggested score $\geq$ 15 as a standard optimal cut off for differentiating PDDs (including autism) from other developmental disorders obtaining sensitivity (Se) 0.85, specificity (Sp) 0.75. A higher cut off $\geq$ 22 was recommended for differentiating between PDD groups which provided Se = 0.75, Sp = 0.60.

Charman *et al.,* (2007) reported the performance of three screening instruments among a sub sample of the SNAP cohort study (n = 199) 9-13 years of age which were completed by parents before diagnostic assessments. The SCQ had a higher AUC = 0.90 compared with the SRS AUC = 0.70 ($p = 0.05$) and the CCC AUC = 0.70 reflecting the SCQ s higher Se = 0.86 and Sp = 0.78. For all three screening instruments group by group comparisons for other ASD vs. non ASD, childhood autism vs. non-ASD and childhood autism vs. other ASD were statistically different whereby scores were higher for the SCQ.

All three screening instruments were unrelated to language ability as measured by the British Picture Vocabulary Scale (BPVS: Dunn *et al.,* 1997) but significantly associated with the Adaptive Behaviour Composite of the VABS and with the parent completed Strength & Difficulties Questionnaire (SCQ: Goodman *et al.,* 2000). Total SCQ scores were highly and significantly correlated for all three screening instruments, and with the ADI-R total score, ICD-10 symptom count, and ADOS-G total score. The SCQ and SRS scores were unrelated to IQ, or language ability as measured by the British Picture Vocabulary Scale (BPVS: Dunn *et al.,* 1987). Score were significantly associated with the Adaptive Behaviour Composite of the VABS and less so with the SDQ.

Chandler *et al.,* (2007) reported the SCQ demonstrated strong discriminate ability at the recommended cut off $\geq$ 15 for differentiating ASDs from other developmental disorders AUC = 0.88, Se = 0.88, Sp = 0.72. IQ total algorithm scores on the ADI-R, ADOS-G, ICD-10 symptom count and SDQ total problem scores were all relevant child characteristics related to the ability of the SCQ to discriminate between ASD and non-ASD cases.

False negatives (FN) cases had lower ADI-R algorithm scores (mean = 32.2, S.E 3.13) than True positive (TP) cases (mean = 40.9 ± 2.2; Z = 1.98; $p < 0.05$). False positive (FP) cases had higher ADI-R algorithm scores (mean = 20.3 ± 1.6 vs. 8.5 ± 1.0; Z = 3.05; $p < 0.01$).

The ($\geq$ 22) cut off point was used for differentiating between childhood autism vs. other ASD cases indicated strong discrimination AUC = 0.93, Se = 0.90, Sp = 0.86. There was no difference between (FN) and (TP) cases in IQ, ADI-R, and ADOS-G algorithm scores, ICD-10 total symptom count, total SDQ score or parental education. Twenty one percent had received an ASD diagnosis from local teams, 71% of the FPs at the 22 cut off point received a consensus clinical diagnosis of other ASDs. All the FPs was given a non-ASD ICD-10 diagnosis following assessment.

Corsello *et al.,* (2007) reported the discriminative validity of the SCQ for differentiating children at the recommended cut off $\geq$15 ASDs vs. other developmental disorders AUC = 0.77, Se = 0.71, Sp = 0.71 were similar for the identification of children with autism from other developmental disorders. However the SCQ was weak for differentiating children with autism from other developmental disorders Se = 0.54 although Sp = 0.84 was high. As in the original study results of independent group t tests indicated that SCQ scores were significantly higher in the AUT (autistic disorder) and ASD groups than the NS (non spectrum disorders) group for all comparisons of diagnostic discrimination and IQ groupings. SCQ scores were significantly higher in the autism vs. ASD groups, than in the NS group, for all comparisons of diagnostic and IQ groupings $p < 0.001$. Correlations were strong and significant between the SCQ and ADI-R total scores $r = 0.73$, $p < 0.001$ the SCQ total score and ADI-R domains $p < 0.001$.

ADI-R total score and chronological age contributed significantly to the total SCQ score, accounting for a significant amount of the variance ($R^2 = .73$, $F(9, 448) = 55.90$, $p < 0.01$) SCQ scores differed significantly by diagnosis within each age group, sensitivity increased with age . The 11 + age group obtained the highest scores, the group most similar in age to Berument *et al*., (1999) sample. There was not a significant difference in scores between the non-verbal (M = 17.66, SD = 7.05) and verbal groups (M = 16.56, SD = 7.91) scores were higher in the non-verbal group.

The SCQ is typically used to screen children for more broadly defined autism spectrum disorders. When classifying Autism vs. NS (Non Spectrum Disorders) the combination of the ADI-R + ADOS resulted in the best sensitivity Se = 0.85 and specificity Sp = 0.87 which also remained strong using the SCQ at the recommended cut off in combination with the ADOS Se = 0.73, Sp = 0.85 compared to using the SCQ alone Se = 0.78, Sp = 0.57.

5.1.5 Factor Analysis

The factor analytic properties of the SCQ were reported in the validation study by Berument *et al*., (1999). Evaluation of three and four factor solutions for the 39 items suggested a four factor model. Principal component factoring with varimax rotation explained 44.4% of the total variation: 24.3% accounted for by the social interaction factor eigenvalue =9.7,α = 0.91; 10.6 % communication factor eigenvalue =3.38, 8.7%, α = 0.71; abnormal language factor eigenvalue = 1.94, 5%, α = 0.79 stereotyped behaviour factor eigenvalue = 1,74), 4.5%) α = 0.67. The alpha reliability coefficient for the total scale was α = 0.90, the individual item to score correlations were positive and mainly substantial in the range 0.26 – 0.73, 23 of the 39 items $\geq$ 0.50.

5.1.6 Discussion

Among the studies reviewed children were referred for assessment for autism spectrum disorder in the following studies Chandler *et al.,* (2007); Charman *et al.,* (2007); Corsello et al., (2007). In the validation study by Berument *et al.,* (1999) children had been previously diagnosed with autism spectrum or other neurodevelopmental disorders. The highest mean scores among the studies reviewed screened older children in restricted age ranges Chandler's study 9-10 yrs of age for childhood autism (mean) (26.6) other ASDs (19.6), and Charman *et al.,* (2007) 9-13 yrs for childhood autism (25.8), other ASDs 19.2 (1.1).

Corsello *et al.,* (2007) reported lower mean scores for children with a diagnosis of childhood autism (20.26) than in Berument study (23.08) even though a both adults and children were screened. Scores in the validation study may have been artificially inflated as parents had been interviewed with the ADI-R prior to completing the screener. The interview experience may have sensitised parents to the questions covered in the SCQ, possibly enhancing the discriminative validity of the screen among the sample. Specific analysis of SCQ items was only performed among one of the studies reviewed.

Berument *et al.,* (1999) reported the majority of items (33 out of 39 items) provided a significant diagnostic differentiation between autism and other neurodevelopmental disorders. The majority of items showed substantial correlations with the total score. Correlations between IQ and SCQ total scores were close to zero (Berument *et al.,* 1999). Charman *et al.,* (2007) reported that sensitivity and specificity remained high for children in both high and low IQ groupings.

Among the studies reviewed Charman *et al.,* (2007), Chandler *et al,* (2007) and Corsello *et al.,* (2007) screened children 2-18 years of age the SCQ sensitivity (range 0.71-0.86) values were higher than specificity (0.71-0.78) values. Although the screen identified the majority of children with a prior diagnosis or those at risk or an autism spectrum disorder, as a consequence of the lower specificity values, a high percentage of children screened will be false positives who do not have an autism spectrum disorder but may be have another unidentified underlying learning disorder i.e. ADHD, Dyspraxia or Speech and Language difficulties in need of assessment.

In the validation study receiver operating curves showed that the total score provided a good differentiation between PDD and other diagnosis sensitivity 0.86, specificity 0.75, PPV = 0.93, NPV = 0.55 but was less effective at discriminating autism from other PDDs at the $\geq$ 22 cut off point sensitivity 0.75, specificity = 0.60. Of the studies reviewed sensitivity and specificity was higher among those that screened older children in restricted age ranges (Charman *et al.,* 2007 Se 0.86, Sp 0.78; Chandler *et al.,* 2007, Se = 0.88, Sp = 0.72).

The poorest performing screen was in Corsello's *et al.,*(2007) study which screened children 2-18 years of age Se 0.71, Sp 0.71, it is interesting to note sensitivity and specificity values were higher in Berument *et al.,* (1999) study Se = 0.85, Sp = 0.75 even though both adults and children were screened in this sample 4-40 years of age. However as explained previously the parents of these children had been interviewed on the ADI-R a number of years previously as participants had been assessed for autism spectrum disorder a number of years previously, may have been sensitised to items in the SCQ which may have inflated scores. This phenomenon may also be evident among the parents of children with a diagnosis on the spectrum who complete the screen as they will educate themselves about the condition when the child has received the diagnosis.

The performance of the SCQ was superior among older children in terms of sensitivity and specificity (Chandler *et al.,* 2007; Charman *et al.,* 2007) compared with younger children Evans et al., 2006a; 2006b; Wiggins *et al.,* 2007; Snow *et al.,* 2008; Oosterling *et al.,* 2010). These findings can be accounted for the fact that almost ½ of the SCQ items relate to a child's behaviour at 4-5 years of age, remaining items relate to current behaviour.

Reduced sensitivity of the screen in younger samples is consistent with the fact that not all autism symptoms included in the SCQ will have emerged in younger children e.g. repetitive routines, imaginative games with peers (Charman *et al.,* 2005; Cox *et al.,* 1999) or not sufficiently for parents to identify these behaviours as noteworthy (Chandler *et al.,* 2007).

Charman *et al.,* (2007) argued enhanced sensitivity and specificity of the SCQ among older children reflect the fuller coverage of the third symptom domain restricted and repetitive behaviours and interests, which are more pronounced among older children on the autism spectrum.

Corsello *et al.,* (2007) reported SCQ scores were higher among older children beginning at 8 years of age, (these findings were not reported in the other studies reviewed) scores differed significantly by diagnostic category within each age group, the 11 + year age group was most similar to the sample in Berument *et al.,* (1999) study, verbal level did not account for lower scores among younger children. Corsello *et al.,* (2007) reported it was not possible to identify a single cut off score that worked equally well across all age groups. It is important to highlight that the data in the studies reviewed is cross sectional, scores may can also be influenced by age of referral and means of recruitment (research vs. clinical).

There were strong correlations between total SCQ scores at the domain level with the ADOS & ADI-R (Berument *et al.,* 1999; Corsello *et al.,* 2007; Charman *et al.,* 2007; Chandler et al., 2007). Corsello *et al.,* (2007) reported false negatives had lower ADI-R scores than true positives, and false positives had higher ADI-R scores. Corsello *et al.,* (2007) reported using a reduced SCQ cut off score $\geq$ 12 in combination with the ADOS resulted in comparable sensitivity to the ADOS + ADI-R combination for differentiating autism from other neuro-developmental disorders. It was not possible to improve sensitivity and specificity to the level comparable to the ADOS + ADI-R for differentiating ASDs from non spectrum disorders.

Only one factor analytic study has been performed of the SCQ in the validation study among a sample previously diagnosed with ASDs and other neurodevelopmental disorders. The findings were clear cut in showing that each of the three domains of symptoms (social deviance, communication deficits, and repetitive behaviours) serves to differentiate PDD but the best differentiation was provided by the total score. Four factors were identified, the findings were provocative in that the communication items spanned the four factors, a few were included in the first factor which was largely associated with social deviance, emphasizing that communication abnormalities are largely connected with problems in social interaction. Many communication items loaded onto the second factor, but those concerned with qualitative abnormal language features (such as verbal rituals and pronoun reversal) loaded separately onto factor 3.

A relatively weak diagnostic differentiation was provided by repetitive stereotyped behaviours, most items loaded onto factor 4, which parallels the ADI and ADOS findings. In terms of measuring repetitive behaviours higher functioning children on the autism spectrum of normal intelligence stereotyped behaviour is more likely to manifest in circumscribed interest patterns than grosser forms of repetitive behaviour. The SCQ only has one item on circumscribed interests there is the requirement to develop better measures for the repetitive features in the behaviours of individuals with mild autism of normal non-verbal intelligence (Berument *et al.,* 1999).

In conclusion the SCQ has been validated in a number of studies among children in different age groups. These studies have primarily recruited high risk samples referred for autism spectrum disorder assessment. The SCQ has not been previously validated in population based samples, or used as a first level screening instrument for autism spectrum disorders. The main advantage of the instrument is the fact that both current and behaviour when the child was 4-5 years of age are included among the items. The screen uses dichotomous scale (yes /no) responses as opposed to measuring degree of severity of a disorder; it may be less sensitive for the identification of children with milder autistic traits with performance IQs in the normal range.

We choose to screen children in a relatively restricted age range 6-11 years of age we suspect the majority of children at risk of an ASD will have come to the attention of education or health authorities and will therefore be identified through screening.

Chapter 2 - Section 6.0

Review of Screening Instruments

Developed for School Aged Children

6.1 Introduction

Three screening instruments developed for screening autism spectrum disorders among school aged children 6-11 yrs of age will be reviewed in this section.
They are as follows:

- Social Responsiveness Scale (SRS: Constantino & Gruber, 2005).
- Childhood Autism Rating Scale (CAST: Williams *et al*., 2005)
- Autism Spectrum Screening Questionnaire (ASSQ: Ehlers *et al*., 1999)

To be appropriate for use in a population setting, an ASD screening test for use among preschool or primary school aged children, needs to be developed for use across different settings e.g. education or primary health care settings. The test must have an established cut off score, validated against standardized diagnostic instruments e.g. ADI-R (Lord *et al*., 1994) and ADOS-G (Lord *et al*., 2000). The test must have established reliability and validity, good sensitivity, specificity and positive predictive value for use in clinical and general population samples (Williams & Brayne, 2006).

6.2 Social Responsiveness Scale (SRS)

6.2.1 Description of the Scale

The Social Responsiveness Scale (SRS: Constantino & Gruber, 2005) represents an attempt to more precisely define the characteristics of children assigned a PDD-NOS diagnosis (DSM IV: APA, 1994). The SRS is a 65 item quantitative measure of autistic social impairments that has been extensively tested in both clinical ascertained and population based samples. The instrument inquires about a subject's ability to engage in emotionally appropriate reciprocal social interactions. Difficulties in these domains are believed to be the core deficiency in all autism spectrum disorders. Reciprocal social behaviours (RSBs) require an individual to be cognizant of the emotional cues of others, interpret these cues appropriately, respond appropriately to what he/she interprets, and to be motivated to engage in social interaction with others (Constantino & Todd, 2005).

The SRS is completed by an informant who has regularly observed the subject in naturalistic social contexts. Informants are instructed to consider only the previous 6 months when rating behaviours. Each item is rated on a scale from 0 (not true) to 3 (almost always true). The instrument takes approximately 15 to 20 minutes to complete. Scores on the SRS are highly heritable (Constantino *et al*., 2003), generally unrelated to IQ (Constantino *et al*., 2003a), and continuously distributed in the general population (Constantino & Todd, 2003). The SRS distinguishes patients with autism spectrum disorders from those with other child psychiatric conditions (Constantino, Przybeck *et al*., 2000; Constantino & Todd, 2003). Items on the SRS are not exclusively limited to RSBs. Items representing the other domains of autistic symptomatology include: 6 items for deficits in social communication and language, and 12 items representing restricted and stereotyped behaviours and interests (Constantino & Todd, 2005).

6.2.2 Distribution of Scores

Constantino & Todd (2003) examined the distribution of autistic traits in the general population among a sample 7-15 years of age, for n = 788 male-male pairs of monozygotic [MZ] and n = 129 dizygotic twins [DZ], n = 319 female-female pairs n = 177 MZ; n = 142 DZ and n = 250 opposite sex pairs who were randomly selected from a large epidemiological twin study.

The (Mean/SD) SRS scores for boys was 25.3 ± 22.0 and for girls 27.5 ± 18.4 , $p < 0.01$. Linear regression analysis revealed a minimum effect for age on SRS scores sex explained only 3% of score variation.

In the general population, characteristics of social behaviour as measured by the SRS are common, continuously distributed, moderately to highly heritable, influenced by the same additive genetic factors in both genders. Exploration of the genetic structure of the SRS by gender was conducted to explain possible causal mechanisms for sex disparities. The best fitting model incorporated only additive genetic influences parameter estimate: 0.76, 95% CI: 0.68-0.80 and unique environmental influences - parameter estimate: 0.24 95% CI: 0.18-0.29. The primary findings was that although heritability estimates for boys were substantially higher than for girls, there was no evidence of the existence of sex specific genetic influences.

Two separate models were used to explain these sex differences. In one model girls were more sensitive than boys to common environmental influences that reduce their pen- trance of genetic liability for autistic traits. The second model, proposed that girls experience a genetic dampening of genetic and environmental influences that operate to bring about these traits, which fits theoretically with existing familial data on autism (Skuse *et al*., 2000)
Mean scores for children with PDDs were more than 2 SD higher than the mean scores for normal children, or children with other psychiatric disorders (Constantino, Przybeck *et al*., 2000). SRS scores were essentially unrelated to IQ (Constantino, Przybeck *et al.*, 2000; Constantino, Davis, Todd *et al*., 2003) but strongly correlated with DSM-IV algorithms. Constantino & Todd (2003) study, social impairments ascertained using the SRS was found to be largely genetically independent from other domains of psychopathologic behaviour. Bolton *et al*., (1994) demonstrated that when diagnostic criteria were relaxed for a full diagnosis of autism to the broader autism phenotype, DZ twin concordance rate increased substantially.

6.2.3 Reliability

Constantino, Przybeck *et al.,* (2000) acquired teacher reports for RSBs in n = 287 school children, 4-14 years of age and n = 158 child psychiatric patients. There were no assessments undertaken in the school sample by the investigators. In the child psychiatric patient sample (with / without PDDs) teachers and parents completed the SRS.
Children included conservative attendees (over a 6 month period) in an outpatient child psychiatric clinic at the Washington School of Medicine.
The SRS demonstrated the following psychiatric properties:

- None of the 65 items was dichotomously endorsed in any score group.
- Internal consistency of the SRS, computed by teachers for children 4-7 yrs Cronbach's alpha = 0.97.
- Stability of SRS scores (test-re test reliability) was obtained for n = 30 clinical subjects (average interval 30-137 days Pearson's r = 0.88. This subsample consisted of non-autistic patients with PDD-NOS n = 9, r = 0.54 non – PDD diagnosis n = 13, r = 0.62, Asperger syndrome n = 8, r = 0.72.
- Parent teacher agreement was obtained for n = 26 clinical subjects rated by teachers / parents Pearson's r = 0.73. This subsample consisted of n = 13 patients with PDDs r = 0.51 and n = 13 non-PDD non child psychiatric patients with a variety of diagnosis r = 0.73.

Although relevant to the validity of the SRS, mean scores indicated greater levels of problems in reciprocal social behaviour (RSB). Scores for children with Autism, Asperger Syndrome, and PDD-NOS were significantly higher than for those with other psychiatric disorders or in the school sample $F = 42.2$; $df = 5$, $p < 0.0001$. The (Mean/SD) for clinical controls was 45.3 ± 29.9 compared with (91.4 ± 32.0) for subjects with PDD-NOS, $t = 5.15$, $df = 46$, two-tailed $p < 0.0001$.

Within each sub group, these were no significant clustering of scores. Approximately (8%) of school children fell above the mean SRS score observed for children with PDD-NOS.
All of these children exhibited some degree of impairment on items representing aspects of the second (impairments in communication) and third (restricted, repetitive, stereotyped patterns of behaviour, interests and activities) of autistic impairments.
Children with PDD-NOS 101.50 ± 23.60 had significantly higher scores than those in the other diagnostic groups conduct disorder 48.4 ± 18.7, psychotic disorders 40.30 ± 8.4, mood disorder 59.40 ± 30.10 and ADHD 51.10 ± 32.90 (single factor ANOVA, $F = 11.69$, $df = 4.75$, $p < 0.00001$).

Constantino, Lavessar *et al.,* (2007) compared teacher ratings of autistic impairments with those derived from parents, expert clinicians, and trained raters for n =577 subjects 4-18 yrs with n=406 and without PDDs n=171. There were strong correlations between parent-teacher SRS scores Pearson's: $r = 0.72$ parent-teacher report SRS subscale scores: social awareness $r = 0.66$, social cognition $r = 0.67$, social communication $r = 0.68$, social motivation $r = 0.57$ and autistic mannerisms $r = 0.69$, all of which were significant $p < 0.001$.

The correlation for teacher report SRS scores between PDD subjects and their male siblings was $r= 0.31$. This is consistent with correlations observed for non-identical siblings in the general population (teacher report: inter class correlations = 0.37 and parent report: inter class correlation = 0.22 (Constantino & Todd, 2003). These findings possibly reflect subtle rater contrast effects, previously described among families with clinically affected children (Duvall *et al*., 2007). Inter correlations between the social and communication scores for both the ADI-R 0.81 & ADOS 0.71 were substantial among verbal subjects in keeping with previous findings on the factor structure of autistic traits (Constantino *et al*., 2004).

Constantino, Abbacchi *et al.,* (2009) examined the longitudinal course of quantitatively characterised autistic social impairments among from n = 95 epidemiologically ascertained male-male twin pairs 3- 18 yrs, and a clinical sample of n= 95 affected children using the SRS at two time points, spaced 1-5 years apart.
In the general population twin sample, over time inter individual differences were highly preserved, from maternal reported SRS scores (inter class coefficient - baseline to follow up ICC = 0.71. There were modest improvements in mean scores SD = 0.5 over the course of the 5 year follow up. As was the case for twins in the general population, inter individual differences among the PDD subjects were highly preserved over time by maternal SRS report ICC = 0.76. There was substantial agreement between mothers and teachers on SRS scores at baseline ICC = 0.66 and follow up ICC = 0.63. Again, there were modest improvement in mean scores over time which reached significance by maternal report (as observed for twins) but not for teacher report. None of the children in the clinical group experienced a magnitude of reduction in maternal SRS scores over the one year period that would be consummate with a loss of a PDD diagnosis.

6.2.4 Validity

Constantino, Davis *et al*., Todd (2003) compared the SRS with the Autism Diagnostic Interview-Revised (ADI-R: Lord *et al.* 2004) among n = 61 child psychiatric patients assessed with both instruments. Participants who had SRS scores that fell within 2 SD of the published mean (100) for PDD-NOS had ADI-R social deficit scores that ranged from 0 – 30. There were no respondents whose ADI-R score fell below the clinical cut off on the SRS score below 65. Mean scores for clinical participants without PDDs were markedly lower than the scores for participants with PDDs.

Murray *et al*., (2011) determined the level of diagnostic agreement between the ADI-R and SRS among a small sample of n=29 children 12-17 yrs diagnosed with high functioning autism, participating in a social skills research training programme. Using a raw cut off score $\geq$ 75, which differentiates children with and without autism, diagnostic agreement between the ADI-R and SRS was 89.7% yielding a moderate kappa k= 0.51. Correlations between total raw scores on the SRS and ADI-R were not significant p = 0.33, explained variance 3.5%. Correlations between the SRS total and the ADI-R Social, Communication and Repetitive Behaviour subscales were also not significant.

Aldridge *et al.,* (2012) investigated the relationship between SRS scores and diagnostic outcome for n=48 children 4-15 yrs 92% male referred to a tertiary level assessment service. The following diagnostic outcomes were obtained: autistic disorder n = 15, 31% Asperger syndrome n = 6, 13%; PDD-NOS n = 14, 29%; non-ASD n = 13, 27. There were no significant differences between SRS scores for the ASD vs. Non – ASD groups Se = 0.64 Sp = 0.85 (optimal screening) teacher scores differed significantly between the two groups Se = 0.77, Sp = 0.67, $p < 0.001$.

The original validation studies suggested the SRS would effectively identify and discriminate children with and without ASDs (Constantino & Gruber, 2005). The results of the present study indicate that the SRS is an effective screening tool with both parent and teacher forms demonstrating high sensitivity.
In the case of children referred for autism specific assessment service the ability of the SRS to discriminate between children with and without autism spectrum disorder was lower than reported in the original validation studies (8% for the parent form; 41% for the teacher form).

6.2.5 Factor Analysis

The factor structure of autistic traits measured by the SRS was examined in three independent samples: a teacher report normal school sample (latent analysis & principal components factor analysis; Constantino *et al.,* (2000) an epidemiological sample of male twin's principal components analysis Constantino, Hudziak *et al.,* (2003); a clinical sample involving n = 266 child psychiatric patients with and without PDDs (cluster analysis and principal components factor analysis; Constantino *et al.,* (2004).

Results of these analyses were consistent in failing to support the existence of independent sub domains of dysfunction in autism spectrum disorders. In each sample, the results supported the existence of a continuously distributed underlying factor, resulting in disproportionate phenotypic manifestations across three criterion domains for Autistic Disorder (social deficits, language deficits, and repetitive / stereotyped behaviours).
Over 25 SRS items had loading factors greater than 0.6 onto the primary factor. Items meeting this criterion represented all three of the DSM IV criterion domains for autism. Analysis of the ROC revealed high degrees of sensitivity and specificity for the screening and clinical cut off scores.

An SRS total raw score of 75 was associated with a sensitivity of 0.85 and specificity 0.75 for any autism spectrum disorder by expert clinician diagnosis, an SRS total raw score of 85 was as associated with sensitivity 0.70 and specificity 0.90 (Constantino & Gruber, 2005).

6.2.6 Discussion

Constantino & Todd (2003) reported that the general population characteristics of social behaviour as measured by SRS score were: continuously distributed, moderately and highly heritable. Influenced by the same genetic factors in boys and girls, and exhibited no evidence of non-additive genetic influences. The existence of sex specific genetic influences appeared to arise from discrepant phenotypic manifestations of genetic and environmental influences common among both sexes. Mean SRS scores for children with PDDs were reported to be more than (2 SDs) higher than mean scores of typical children and other with psychiatric disorders not on the autism spectrum (Constantino & Prezbeck *et al*., 2000). SRS scores were not related to IQ (Constantino & Prezbeck *et al.,* 2000; Constantino & Davis *et al.*, 2003). Internal consistency for teachers and parents has been reported to be high among parents and teachers for children with and without PDDs (Constantino & Prezbeck *et al*., 2000) and between mothers and fathers for the quantitative assessment of autistic deficits (Constantino, Davis, Todd *et al*., 2003). Scores have been reported to be strongly correlated with the DSM-IV algorithm scores from the ADI-R and largely genetically independent of other domains of psycho pathologic behaviour (Constantino, Hudziak, Todd *et al.*, 2003), for younger and older subjects (Constantino, Davis, Todd *et al.,* 2003).

The SRS may prove to be as effective at characterising controls as scores are not impacted by floor effects, therefore individuals with extreme low levels of impairment are identifiable (Constantino & Prezbeck *et al*., 2000). When teacher and parent SRS scores were used to characterise a given subject, elevated scores from both informants was associated with a high degree of diagnostic accuracy (Constantino, Lavessar *et al*., 2007). Aldridge *et al.,* (2012) investigated the clinical utility of the SRS in a tertiary level autism specific assessment service as completed by both parents. However children with behavioural and mood disturbances can obtain high scores on the SRS (Pine *et al*., 2008; Charman *et al*., 2007) referred to autism specific assessment services.

6.3 Childhood Autism Spectrum Test (CAST)

6.3.1. Description of Scale

The Childhood Autism Screening Test (CAST: Scott *et al.,* 2002) was developed for screening school aged children 4 -11 years of age for Asperger syndrome (AS) and related social communication difficulties. The screening instrument was developed based on behavioural descriptions of ICD-10 (WHO, 1992) and DSM IV (APA, 1994) core features of autism. Some items in the CAST were based on items appearing in two other screening tools: The Pervasive Developmental Disorders Questionnaire (PDDQ: Baird *et al*., 2000) and the Asperger Syndrome Screening Questionnaire (ASSQ: Ehlers *et al.,* 1999).

Neither the PDDQ nor the ASSQ are considered appropriate tools for screening for AS in primary school aged children as the ASSQ was only validated in a clinical sample. The PDDQ was not developed to specifically screen for AS. The questions in the CAST were developed to cover the whole range of behaviours to facilitate detection at the high functioning end of the autism spectrum. The CAST has 37 items, 31 are key items contributing to a child's total score. The remaining 6 are control items on general development and not included in the total score (ASSQ: Ehlers *et al.,* 1999).

6.3.2 Distribution of Scores

Williams *et al*., (2008) explored the sex distribution of CAST scores among (n = 11,635) school children 6-9 yrs, n = 3,370), 29% were returned. The median score was significantly higher in boys median = 5, IQR = 3.8 girls median = 4, IQR 2.6, median test, $p < 0.001$. The shape of the score distributions differed by gender, with a longer tail at the upper end of the distribution for boys. The distributions of scores were similar by age there were no interaction effects for gender and age.

6.3.3 Reliability

Allison *et al*., (2007) investigated the test – retest reliability of the CAST in the same cohort as the previous study. Parents of children who obtained scores $\geq$ 12 were invited for their child to attend a full diagnostic assessment. At the time of assessment parents were asked to complete a second identical copy of the CAST 2 (time interval: 2 months) prior to administration of the ADI-R & ADOS. The correlation coefficient (Spearman's rho) between CAST1 and CAST2 was 0.67, $p < 0.001$.

The median differences between scores were -2 IQR -4 -0, a high proportion of children deceased in score (63%) while 23.2% increased in score. The kappa statistic for agreement across scores ($\leq$ 15 and $\geq$ 15) was k = 0.46 p < 0.001. Overall agreement was 72.6%: 95% CI: 0.61-0.82, children were more likely to decrease in score group than to increase.

6.3.4 Validity

In a validation study of the CAST by Scott *et al.,* (2002) a return rate of (n=199, 17%) was obtained from parents for children 4-11 yrs screened for AS attending mainstream primary schools in Cambridgeshire. The majority of CAST questions (35/37: 95%) differentiated children with an ASD diagnosis from typically developing peers. Both the CAST and SCQ were completed by (n = 139, 80%) of parents – the SCQ was posted to parents on completion of the CAST. Eighty seven percent of diagnosed cases of autism spectrum disorder were correctly identified by the CAST compared with 62.50% of cases identified with the SCQ. Williams *et al*., (2005) screened a sample of 5-11 year olds enrolled in mainstream schools in Cambridgeshire, based on a response rate of 26% using a cut off score $\geq$15 sensitivity Se = 1.0 and specificity Sp = 0.97 were strong for differentiating ASDs from other developmental disorders.

6.3.5 Discussion

The CAST has been validated in the general population by Scott *et al.*, (2002), Williams *et al*., (2005; 2008) and Allison *et al*., (2007) in mainstream schools, the screen was not administered among high risk groups enrolled in special education schools. The response rates in these studies from parents to complete the instrument has been extremely low ranging from 17% - 26% and therefore not representative of the population screened. Allison *et al.,* (2002); Williams *et al*., (2005) reported modest test – retest reliability for the CAST over an average of two months, scores in the moderate to high range were unstable. Children were likely to move down score over time, so there is the potential for a high rate of false negatives. Sensitivity and specificity of the CAST was superior to the SCQ, which was completed after the CAST, fatigue effects, and/or completion of the first screen could have influenced scores obtained on the SCQ. The authors were unable to account for the difference in scores between the two screens. Williams *et al*., (2005) reported high sensitivity and specificity for the CAST but positive predictive value was low 26%, only a sample of low scorers were invited for assessment.

Response bias was evident in a comparison of the number of children known to schools and the number of cases identified through the screener. The screen missed 3/5 known cases as many of the previous diagnosis related to non-responder cases.

6.4 Autism Spectrum Screening Questionnaire (ASSQ)

6.4.1 Description of Scale

The Autism Spectrum Screening Questionnaire (ASSQ: Ehlers & Gillberg, 1993) was originally developed as a joint project involving the present authors for use as a first level population screening instrument for Asperger syndrome in mainstream schools. Pools of items were chosen by the authors considered to best reflect the characteristics of Asperger syndrome in children 7-16 years of age, based on the author's long term clinical experiences and review of pertinent literature (Bowman, 1988; Gillberg & Gillberg, 1989; Kerbeshian & Burd, 1986; Rutter & Schopler, 1987; Tantam, 1988; van Krevelen 1971; Wing, 1981; Wing & Gould, 1979; Wolff & Berlow, 1979).

Several preliminary drafts of the Swedish version of the instrument were tested in collaboration with special education teacher in Goteborg. The ASSQ comprises 27 items rated on a 3 point scale 0 = no abnormality, 1 = some abnormality or 2 = definite abnormality range of possible scores 0-54. Eleven items tap topics regarding social interaction, 6 items communication problems, 5 items restricted and repetitive behaviour. The remaining items embrace motor clumsiness and other associated symptoms including motor and vocal tics.

6.4.2 Distribution of Scores

Posserud *et al*., (2006) assessed the distribution of scores in a total population of mainstream children (n= 9430) 7-9 years of age. 2.5% of the population scored $\geq$ 15. There were large differences between informant's scores: parents report symptom range: 1.1% - 45.8% teachers report symptom range: 0.9% - 17.5%. Boys obtained higher scores than girls on both the parent ratio 2.1:1 and teacher forms 5.1:1 gender ratios remained high for teacher assessments even when lowering the cut off score. There was no significant effect of age on mean symptom scores.

6.4.3 Reliability

Ehlers, Gillberg, Wing (1993) reported a test re test reliability coefficient of r = 0.90 among teacher ratings across an 8 month interval and a inter rater reliability coefficient r = 0.79 for teacher-teacher agreement. Ehlers *et al.,* (1999) reported a test re test reliability coefficient for teacher r = 0.94 and parent ratings r = 0.96. Inter-rater reliability for both parent-teachers over a two week interval was r = 0.77 for children subsequently diagnosed on the autism spectrum. Correlation coefficients across informants for each diagnostic group were significant for autism r = 0.77, $p < 0.0001$, ADHD r = 0.27, p = 0.0385, but not a general category of learning disorders r = 0.19, not significant; mean inter rater difference were also not significant across diagnostic groups (Ehlers, Gillberg, Wing 1999).

6.4.4 Validity

Ehlers, Gillberg *et al.,* (1993) reported Pearson correlations between parent ratings on the ASSQ r = 0.75, $p < 0.0001$, Connor's scale r = 0.58, $p < 0.0001$. Correspondence between teacher ratings on the ASSQ and the following scales: Rutter scale r = 0.77, $p < 0.0001$, Connor's scale r = 0.70, $p < 0.0001$. Parent T score cut offs $\geq$ 13 and teacher T score cut off $\geq$ 11 maximised specificity identifying 91-90% respectively for cases of autism spectrum disorder, false positive rate n = 23, 42%.

The optimal cut off score established for differentiating Autism Spectrum Disorder from other psychiatric disorders was $\geq$ 19 (parent ratings) identified 62% of true positives (ASDs) with a rate of only 10% false positives. Cut off $\geq$ 22 for teacher ratings yielded a true positive rate of 70%, 9% false positives. Posserud *et al*., (2009) screened children 7-9 years of age who were participants in the Bergen Child Study (2002) reported an area under the curve that indicated strong discriminate validity for both parent Se = 0.91 Sp = 0.77 and teacher Se = 0.83, Sp = 0.87 ratings.

6.4.5 Factor Analysis

Posserud *et al*., (2008) undertook a factor analytic study of the ASSQ using data from the Bergen Child longitudinal Norwegian Study for school children attending 2nd and 4th grades (average age 8 years of age). Principal Components Analysis (PCA) and Principal Factor Analysis (PFA) were undertaken on a sample of n = 6229 children were performed where both parent and teacher ratings were available. Internal consistency of the ASSQ items was good, Cronbach alpha values of 0.89 (teacher reports) and 0.86 (parent reports).
The factor analysis revealed a highly stable three factor structure for both parents and teachers ratings. Factors were named "social differences" "tics/motor/OCD" and "autistic style" based on the item loading on each factor.

The validity of the factors was further established through correlation with the Strengths and Difficulties Questionnaire (Goodman et al., 2000) and sub scales. Both the total ASSQ score and "social difficulties" factor were found to be highly correlated to the (SDQ) peer problems subscale. The tics/motor/OCD factor and "autistic style" both correlated highest with the peer problems subscale, the correlations were only in the intermediate range.

6.4.6 Discussion

The test re-test reliability of the ASSQ was reported by the test developers over a two week interval as high (Ehlers & Gillberg, Wing 1999). Posserud *et al*., (2008) found that internal consistence of ASSQ items for both teachers (Cronbach alpha) 0.89 and parents 0.86 was good. Posserud *et al*., (2006) reported 2.7% of children obtained high scores on the ASSQ had some degree of psychiatric pathology as indicated by the high rate of referrals to child mental health clinics. Unlike the SRS only one format of the screening instrument was developed for completion by both parents and teachers. Parents reported higher symptoms than teachers, boys obtained higher scores than girls by both informants.

Ehlers & Gillberg *et al*., (1999) found that there was an overall tendency for teachers to score children on average 2 point higher than parents. A more recent study by Posserud et al., (2009) found that 90% of children who received a diagnosis of autism or broader autism phenotype screened positive on the parent or teacher ASSQ at the 98th percentile. Diagnostic accuracy was further improved combining scores from both informants.

In this study the instrument proved to be effective at identifying low and high functioning children on the autism spectrum. Children with MR and boarder line intellectual functioning were more common among the false positives.

6.5 Final Comment

The Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as discussed in the previous chapter and Social Responsiveness Scale (SRS: Constantino & Gruber, 2005) are the most extensively evaluated screening instruments developed for screening school aged children for autism spectrum disorders. The former has been primarily validated in studies among preschool the most recent of these were undertaken by Evans et al., 2006a; 2006b, Allen *et al.,* 2007, Wiggins *et al.,* 2007, Snow *et al.,* 2008, Oosterling *et al,* 2010). A limited number of studies included school aged children (Chandler et al., 2007; Charman *et al.,* 2007, Corsello *et al.,* 2007). The validation study by Berument *et al.,* (1999) included both children and adults 4-40 yrs of age. With the exception of the validation study, children screened were referrals for assessment for autism spectrum disorders.

Scores were unrelated to IQ and strongly correlated with the ADI-R and ADOS (Berument et al., 1999; Charman *et al.,* 2007). Chandler *et al.,* (2007) reported false negatives had lower scores than true positives while false positives had higher ADI-R scores. Overall sensitivity and specificity of the screen was higher among older children screened in restricted age ranges. Corsello *et al.,* (2007) who screened children 2-16 years of age reported scores increased with age, as did sensitivity and specificity of the screen. It was possible to identify a specific cut off point on the screen for children in different age groups. The main advantage of the SCQ is that items relate to current and behaviour at 4-5 years of age (almost ½ of the items). The main disadvantage of the screener is the fact that it measures "caseness" dichotomously (yes / no) format questions, the same format as the ADI-R and ADOS as opposed to degree of severity as measured by other screens reviewed, scores exhibit floor effects on re-administration of the screen over a defined interval.

Although the SRS has been validated among epidemiological samples, the majority of these studies were longitudinal cohort twin studies (Constantino & Todd, 2000; 2003; Constantino, Hudziak, Todd (2003); Constantino & Todd, 2005; Constantino, Abbacchi *et al.,* 2009) based prevalence studies. A limited number of studies recruited clinical samples, those that did were reviewed by Constantino, Przybeck, Friesen, *et al.,* (2000), Murray et al., 2011, Aldridge *et al.,* 2012, one study was undertaken among primary school children (Constantino, LaVesser *et al.,* 2007).

Constantino & Prezbeck *et al.,* (2000) reported that children screened with the SRS scores were 2 standard deviations higher than typically developing children, and largely independent of other domains of psycho pathology. The authors also reported high internal consistency between parents and teachers, Constantino, Davis, Todd *et al.,* (2003) reported high internal consistency between mother and fathers. As with the SCQ scores are not related to IQ and highly correlated with the ADI-R and DSM-IV. The two main advantages of the SRS is the fact that both parent and teacher forms of the instrument had been developed, autistic traits are measured on a continuum reducing the risk of missing higher functioning children in terms of performance IQ. The primary drawback of the screen is the fact that informants are only asked to consider the previous six months for rating the child.

The CAST has not been validated to the same extent as the SCQ or SES. The CAST was used as a first level screener in studies by Scott *et al.,* (2002) and Baron-Cohen *et al.,* (2009), response rates from parents to complete the screen in these prevalence studies were extremely low, and not representative of the populations screened. Allison *et al.,* (2007) reported a significant number of children decreased in score on reassessment over a 2 month interval indicative of a high false positive rate.

The ASSQ has been used in recent autism prevalence studies Ellenfsen *et al.,* (2007) and Kim *et al.,* (2011). There were a number of methodological problems with these studies in the former teachers selected children who in their opinion were at risk of an ASD and required ASSQ screening. In the latter study the number of children recorded with learning disabilities on the disability register was at odds with the extremely high prevalence rate reported by the study authors.

Although test re test reliability reported by Ehlers & Gillberg (1993) was high for both parent and teacher ratings, and sensitivity, specificity demonstrated in the Bergen Longitudinal Study (2002) was good a limited number of studies have been performed in both clinical and epidemiological samples to recommend the instrument for use as a first level screener in population studies.

Chapter 2 - Section 7.0

Diagnosing Autism Spectrum Disorders

7a Medical Evaluations

7.1 Identification of Developmental Difficulties in Infancy & Early Childhood

Autism is a pervasive developmental disorder that is usually apparent from early childhood (Volkmar, Stier, & Cohen, 1995). It is characterized by profound deficits in communication, social understanding and by ritualistic and obsession behaviours (Howlin, 1998).
It is now widely accepted, that autism has an onset in infancy or early childhood (Volkmar *et al.* 1985) and many parents have serious concerns about their child development in the first year of life (Firth, Soares & Wing 1993; Gillberg *et al.,* 1990).

Parental concerns sometimes emerge in response to an unusual rate of progress (e.g. delays in reaching developmental millstones) apparent slowing of development (e.g. babbling is not followed by the emergence of first words), or loss of previously acquired skills (Siperstein & Volkmar, 2004).

As children grew older, the pattern of cognitive development is largely affected by their degree of cognitive impairment. Although the syndrome of autism can occur in individuals of all levels of ability, the majority (70-75%) have some associated learning disability, around (50%) have an IQ (<50). In those with severe to profound cognitive impairment useful speech is unlikely to develop; this group also tends to develop more disturbed behaviours, such as self-injury, and will almost invariably require special education and lifelong care (Howlin, 1998).

Despite accumulating evidence that signs of autism spectrum disorders are present in early infancy, the interval between many parents' first concerns and a definitive diagnosis is approximately 3 to 4 years (Mandell, Palmer *et al.,* 2005). This interval increases to as high as 9 years for children diagnosed with higher functioning autism phenotypes e.g. AS/HFA/PDD-NOS (Young *et al,* 2003; Baron-Cohen *et al,* 1992; Howlin & Asgharian, 1999; Howlin, 1998).

The current diagnostic classifications ICD-10 (WHO, 1992) and DSM-IV-R (APA, 2000) have not been developed to identify behaviours on the autism spectrum that might be considered prominent at different ages of a child's development. Some of the behaviours outlined in the DSM-IV-R (APA, 2000) are rarely observed in children under two years of age, yet become pronounced as the child grows older (Cox *et al.,* 1999; Howlin & Asgharian, 1999; Stone *et al.,* 1999).

Recent studies have report that Autism Spectrum Disorders are fairly stable neuropsychiatric disorders (Cederlund *et al.,* 2008: Charman *et al.,* 2005; Chawarska *et al.,* 2007; Kleinman *et al.,* 2008; Lord *et al.,* 2006; Moss *et al.,* 2008; Turner *et al.,* 2006) with diagnostic stability estimates ranging from (69%) (Lord *et al.,* 2006) to (95%) throughout childhood (Charman *et al,* 2005). Diagnostic stability has been linked to age at clinical evaluation, cognitive and language ability, and participation in early intervention (Itzchak & Zachor, 2009; Stone *et al.,* 1999; Turner & Stone, 2007).

7.2 Regression

Although parents often have developmental concerns about the child before 12 months of age, there is a cohort of children who appear to develop typically in the first 15 to 21 months of life prior to the onset of regression (Barbaro & Dissanayake, 2009). These children reach appropriate language and social skill milestones, but then progressively lose these skills, between 13 and 18 months (Werner & Dawson, 2005; Goldberg et al, 2003; Kurita, 1985; Volkmar *et al.,* 1985; Volkmar *et al.,* 1988). Regression occurs in approximately (20-49%) children with autism spectrum disorder (Kurita, 1985; Davidovitch *et al.,* 2000; Filipek *et al.,* 1999; Honshino *et al.,* 1987; Siperstein & Volkmar, 2004). The most frequent skill loss reported by parents is language, followed by social skills (Goldberg *et al.,* 2003; Davidovitch *et al*., 2000; Siperstein & Volkmar 2004).

In the majority of cases the child's development was not in the normal range before the loss of previously acquired skills was evident (Siperstein & Volkmar 2004; Brown *et al.,* 1995). Regardless of the pattern of onset, any child with an autism spectrum disorder can show signs of regression, in which existing skills, particularly spoken language (Landa *et al.,* 2007; 2005; Cox *et al.,* 1999; Luyster *et al.,* 2005) and social emotional reciprocity (Landa *et al,* 2007; Luyster *et al*., 2005) are diminished or lost altogether.

Atypical patterns of behaviours emerge e.g. temperamental and sensory deregulation or repetitive and stereotyped patterns of behaviour and interests (Bryson *et al.,* 2007; Landa e*t al.,* 2005; 2007). Language regression in autism does not rule out the possibility of the reacquisition of language skills later in life, nor does it predict more severe impairment in language skills (Goldberg *et al.,* 2003).

7.3 Differential Diagnosis

Co-morbid behavioural disorders are common among children with autism spectrum disorders include: Attention Deficit Hyperactivity Disorder (ADHD), Deficits in Attention, Motor skills and Perception (DAMP), oppositional behaviour, resistance to change, acutely anxious behaviour and particular fears in certain situations (Charman & Baird, 2002). Eating and sleeping problems, although common in young children, are seen to a more extreme extent in children with an Autism Spectrum Disorder. Clumsy features may overlap (Charman & Baird, 2002), in excess of 50% of children present with co-ordination difficulties (Manjiviona & Prior, 1995). Tactile defensiveness (Baranek *et al.,* 1997) is one of a range of hypersensitivities commonly encountered. Strong aversion to everyday noises and specific interests relating to sensory experiences such as touch or smell are common (Charman & Baird, 2002).

Children with specific language impairments, not only have difficulty in processing language, but may also have difficulty in processing other kinds on communication (Boucher, Lewis, & Collins, 2000).

Severe receptive difficulties may lead to adherence to routines, limited imaginative play skills, and peer based social competence. Even where there has subsequently been significant progress with language development, social impairments remain very significant and signs of Autism Spectrum Disorders often become more marked in middle childhood (Michelotti *et al.,* 2002)

There is evidence that the extent of language delay itself is an index of the severity of Autism Spectrum Disorders, and that language delay accounts for some social and communication impairments (Lord & Pickles, 1996 & Lord & Risi, 1998).

Specific impairments in social communicative features: social interest e.g. offering to share, use of pointing, eye gaze, and other non-verbal gestures to regulate attention, and measures of facial expression are related to language ability (Lord & Pickles, 1996). Other features that differentiate Autism Spectrum Disorder from language disorders include: impairments in empathy and imitation, indifference to praise, impaired make believe play, peculiar speech patterns and unusual and bizarre responses to the environment (Mayes, Volkmar, Hooks, & Cicchetti, 1993).

Differential diagnosis of children with Asperger Syndrome is at times complicated by the fact that the condition may coexist with other behavioural disorders e.g. Tourette syndrome (Gillberg, 1989) ADHD, anxiety and mood disorders, learning disability, motor clumsiness, antisocial behaviour, and unusual social interactions (Gillberg, 1989; Szatmari, *et al.,* 1995). Sometimes children with Asperger syndrome are initially diagnosed as aphasic or dysphasic due to their difficulties processing language in the same way as normal children (Siegel, 1996).

Stereotyped patterns of behaviour are observed in children with a diagnosis of Asperger syndrome and Obsessive Compulsive Disorder (APA, 1994). Asperger Syndrome is characterised by qualitative impairments in social interaction with more restricted patterns on interests and activities (Gillberg, 1989). Although significant general language delay is an exclusionary feature in the diagnosis of Asperger syndrome, delays in the acquisition of language have been reported in over one third of clinical examinations (Campbell & Shay, 1995).

7.4 Co-morbid Medical Conditions

7.4.1 Seizure Disorders

The prevalence of seizures in adults with autism has been estimated to be between 20% to 30% (Minshew *et al.,*1997) and in children between (20%) to (35%) (Rapin *et al.,* 1996; Tuchman *et al.,* 1999) with peak periods said to occur during early childhood and adolescence (Volkmar & Nelson, 1990). All types of seizures have been found in association with ASD, including: major motor, myoclonic and febrile seizures, complete partial seizures are said to be most frequently reported (Bauman, 2010).

Sixty seven percent of seizures that occur in ASD become apparent after 12 years of age (Rossi *et al.,* 1995) with 30% occurring by 20 years of age. The development of seizures appear to be associated with low cognitive ability, dysmorphic features, motor impairment, syndromes including but not limited to tuberous sclerosis and Rett's syndrome (Bauman, 2010).

7.4.2 Sleep Disorders

Sleeping problems are highly prevalent in children with ASD, and rank as one of the most common concurrent clinical disorders (Ming *et al.,* 2008). Prevalence rates vary widely, ranging from (40%) to (80%) (Richdale, 1999; Johnson *et al.,* 2009) as compared to that of typically developing children in which prevalence rates are approximately (30%) (Feber, 1996). Among the sleep problems most commonly reported, sleep onset, sleep maintenance, and sleep duration, are consistently the most predominant concerns expressed by parents of children with ASD (Malow *et al.,* 2006).

7.4.3 Gastrointestinal Disorders

The reported prevalence of gastrointestinal symptoms (GI) in children with ASDs range from (9%) to (70%) or higher (Nikolov *et al.,* 2009; Ming *et al.,* 2008; Valicenti-McDermott *et al.,* 2006). Andrew Wakefield (1999) published in the Lancet, a study in which reported bowel symptoms in a prospective sample of 12 consecutive vaccinated children diagnosed with autism spectrum disorders, and other disabilities. Wakefield alleged a possible connection with the MMR vaccine and development of autism among these children. He described the endoscopic findings in these children diagnosed with autism, revealing nodular hyperplasia, mucosal abnormalities, including non-specific inflammation.

Although controversial this study drew a lot of attention into the gut pathology, as a possible underlying cause of autistic behaviour (Cubala-Kucharska, 2010). Horvath *et al.,* (1999) preformed endoscopies on a group of 35 non-verbal autistic children, revealing by histological examination evidence of grade I or grade II reflux esophagitis in (69.4%), chronic gastritis (41.2%), and chronic duodenitis in (66.7%) low carbohydrate digestive enzymes and increased pancreato- biliary secretion after administrating of secretine. Kugathasan *et al.,* (2001) linked autism to inflammatory bowel disease of autoimmune origin. The most common GI symptoms and signs reported for persons with ASDs are chronic constipation, abdominal pain with or without diarrhoea, and encopresis as a consequence of constipation have also been reported among children with ASD. Other GI conditions include: GERD, abdominal bloating, and disaccharidase deficiencies and pathologic findings such as inflammation of the gastrointestinal tract and abnormalities of the enteric nervous system (Buie *et al.,* 2010). Clinical practice guidelines for the management of ASDs do not included routine consideration of potential GI problems (Johnson *et al.,* 2007; Volkmar, Cook, Pomeroy *et al.,* 1999; Filipek *et al.,* 2000; Myers *et al.,* 2007).

An emerging literature suggests that individuals with ASDs and GI symptoms may be at a higher risk of behavioural problems (Lord & McGee, 2001). Vocal and motor behaviours, including problems behaviours such as: self-injury and aggression sleep disturbance and irritability, may be behavioural manifestations of abdominal pain or discomfort in persons with ASDs (McAtee *et al.,* 2004; Carr *et al.,* 2007). A few studies have suggested relationship between gastrointestinal inflammation and GI symptoms associated with ASDs. In children with ASDs, immune histochemistry and flow-cytometry studies have consistently shown marked pan-enteric infiltration of lymphocytes in the gut mucosa (Ashwood *et al.,* 2003; Furlano *et al.,* 2001).

7.4.4 Metabolic Disorders

Metabolic disorders are considered to be relatively rare among individuals with neuro developmental disorders. Among this population, the estimated diagnostic yield has been found to vary from (1% ~ 2.5%) (Van Karnebeek, 2005). There is a growing body of suggestive evidence that mitochondrial dysfunction may play a role in at least a subset of individuals with ASD (Bauman, 2010).

At the present time, the prevalence of mitochondrial disorders in ASD is largely unknown. Oliveria *et al.,* (2007) published a population based study of school aged children with ASD. The investigators found that (7%) of their subjects met criteria for a definitive mitochondrial respiratory chain disorder.

7.5 Medical Investigations

7.5.1 Clinical Examination

First line investigations for learning disability and developmental delay (McDonald., Rennie., Tolmie., 2006) may still be relevant in the context of ASD, and might include the investigation of urea and electrolytes, creatine kinase, thyroid function tests, urate, full blood count, ferritin and biotinidase (O'Hare, 2009).

There can be potential hypothyroidism in 22q11 deletion and low calcium in William syndrome, both of these conditions have a higher rate of ASD than the general population (Gillberg., Aicardi., Bax., 2009). Dietary intakes in ASD can be faddy and nutritionally inadequate (Herndon., DiGuiseppi., Johnson *et al.,* 2009). Given the high prevalence of autism in Tuberous Sclerosis Complex (TSC) an examination using (Wood lamp) should be performed on every child presenting with possible autism (Reich, Lenoir, Malvy *et al.,* 1997; Smalley *et al.,* 1992).

There have been reports of certain metabolic diseases associated with autism, although these probably occur in (< 5%) of cases (e.g. inborn errors in amino acids, carbohydrates, purine, peptide, and mitochondrial metabolism (Filipek *et al.,* 1999, Page., 2000; Dykens & Volkmar, 1997; Rutter., Bailey., Simonoff *et al.,* 1997). Because no particular metabolic abnormality has been widely seen in this population, specific screening is recommended only as indicated by patient's clinical presentation on history and physical examination (e.g. episode vomiting, lethargy, encephalopathic changes, very early onset seizures, dysmorphic features suggestive of storage disease, significant hypotonia, and/or questionable history of proper newborn screening) (Spence, Sharifi, Wiznitzer, 2004).

There are relatively few non genetic causes of ASD presently recognised, those that have been cited include: rubella embryopathy, herpes encephalitis, cytomegalovirus intrauterine infection, retinopathy of prematurity and thalidomide embryopathy (Gillberg., Aicardi., Bax 2009) . Population based studies have included foetal alcohol syndrome (Kielinen *et al.* 2004) and prenatal exposure to Valporate (Muhle *et al.,* 2004).

7.5.2 Genetic Testing

ASDs are complex neurodevelopmental disorders with a strong genetic base (Olivie, 2012). The role of genetics in ASD is suggested by a 15 – to 20 – fold higher recurrence rate of autism in siblings of affected children compared to the general population and by a (60 – 90%) ASD concordance reported for monozygotic twins are, opposed to (10%) for dizygotic twins (Levy, Mandel, Schultz, 2009). Relatively few non genetic causes of ASD are recognised. These are some evidence which suggest that the following prenatal risk factors are associated with the development of ASD which include: herpes encephalitis, congenital intrauterine infection (e.g. rubella embryopathy), foetal alcohol syndrome, and prenatal exposure to valporate (O'Hare, 2009).

Chromosomal abnormalities have been reported in (5%) to(9%) of patient with ASD (Wassink *et al.,* 2001, Challman *et al.,* 2003) with case reports of abnormalities on almost every chromosome (Gillberg, 1998; Lauritsen *et al.,* 1999). There is an association with duplication on chromosome 15q in Prader-Willi syndrome (Weidmer-Mikhail *et al.,* 1998; Wolpert *et al.,* 2000; Schroer *et al.,* 1998; Cook *et al.,* 1997). The highest yield of cytogenetic testing is probably in the population of patients with significant dysmorphology and/or MR (Rutter, Bailey, Bolton *et al.,* 1994; Miles & Hillman., 2000; Konstantareas & Homatidis., 1999).

The American Academy of Neurology practice parameters perform standardised karyotyping and DNA analysis for fragile X in any autistic child with MR, or a family history of fragile X, undiagnosed MR or dysmorphic features (Spence, Sharifi, Wiznitzer, 2004). Fragile X syndrome (FXS) is the most common cause of inherited intellectual disability (Olivie, 2012). Girls with FXS are typically less affected cognitively than boys as a result of the modifying effect of a second (normal) X chromosome (Hagerman, 2011). Other monogenic syndromes associated with ASD account for approximately (10%) of cases (Olivie, 2012), examples include: tuberous sclerosis, neurofibromatosis, and 22q11 deletion (Steyaert & De la Marche, 2008).

7.5.3 Audiologic Evaluation

All children with developmental delays, especially those with delays in social and language development should undergo a formal audiologic hearing evaluation. Concern regarding a speech, language, or hearing problem (loss of sensitivity, inconsistent responses, no response, or unusual response to sounds or sound sources) should result in immediate referral for audiologic assessment. This referral should occur regardless of the child having passed a neonatal hearing screen (Filipek *et al.,* 1999). Hearing loss (conductive, sensorineural, or mixed) can occur with autism: children with autism may be incorrectly thought to have peripheral heating loss (Adkins & Aissa, 1979; Jure, Rapin, & Tuchman, 1991; Klin, 1993). Audiologic assessment should occur early in the differential diagnostic process, and include a battery of tests including: behavioural audiometric measures, assessment of middle ear function and electrophysiological procedures (American Speech-Language Hearing Association, 1991).

When hearing loss (conductive or sensorineural) is detected the child should be referred to an otolaryngologist, but concerns at Level I screening regarding other developmental indicators ('red flags') for autism (e.g. lack of social relationships, unusual behaviours) must also be followed up. Transient, fluctuant conductive hearing loss associated with otitis media with effusion can occur in children with autism. Audiologic and medical follow up for conductive hearing loss associated with recurrent otitis media is important in the long term management of children with autism (Filipek *et al.,* 1999).

7.5.4 Imaging

Current published guidelines state that routine structural neuroimaging is indicated only in cases where there are seizures are some sort of focal abnormality (Filipek., Accardo., Ashwal., 2000; Geschwind., Cummings., Hollander et al., 1998; Volkmar., Cook., Pomeroy., 1999). From a research perspective, methodological and sample issues make it difficult to interoperate the significance of results or to reproduce (Cody *et al.,* 2002).

7.5.5 Electroencephalography

A high incidence of epilepsy has been reported in the ASD population, prevalence estimates can range from (5%) to (40%) (Tuchman *et al.,* 1991; Volkmar *et al.,* 1990., Minshew *et al.,* 1997). Some evidence has suggested that epilepsy and/or abnormal EEG activity is more common in children who have suffered language regression.

Seizure onset appears to occur in a bimodal age distribution, very common in young children, and again in adolescence (Minshew *et al.,* 1997). ASD patients with isolated epileptiform EEG abnormalities in the absence of clinical seizures have also been reported, with varying rates from (15%) to (30%) (Minshew *et al.,* 1997; Tuchman & Rapin., 1997; Rossi *et al.,* 1995; Kawasaki *et al.,* 1997). There is some evidence that prolonged or overnight EEGs may yield higher rates 46% (Tuchman *et al.,* 1997).

7b Psychological Assessments

7.6.1 Introduction

Autism is diagnosed by the presence of observed behaviours and symptoms rather than by aetiology (Minshew *et al.,* 2001;Mundy & Markus, 1997; Mundy & Sigman, 1998a; 1989b; Mundy *et al,* 1993).

Diagnostic guides for the assessment of Autism Spectrum Disorders have been published by:

- The American Academy of Child and Adolescent Psychiatry (Volkmar *et al.,* 1999).
- American Academy of Neurology (Filipek *et al.,* 2000).

The American Academy of Neurology - Level II diagnosis and evaluation for autism states that clinicians must rely on their clinical judgement, aided by guides to diagnosis, results from the various assessment instruments, rating scales and checklists. The diagnosis of autism should include the use of a diagnostic instrument with at least moderate sensitivity, and good specificity for autism. Sufficient time should be planned for standardised parent interviews regarding current concerns and behaviour history related to autism, and direct, structured observation of social, communicative behaviour and play (Filipek et al., 2000).

The following instruments were recommended (Filipek., Accardo., *et al.,* 1999):
Diagnostic parental interviews –

- Gilliam Autism Rating Scale (Gilliam, 1995).
- Parent Interview for Autism (Stone & Hogan, 1993).
- Pervasive Developmental Disorders Screening Test – Stage 3 (Siegel, 1998).
- Autism Diagnostic Interview – Revised (Lord *et al.*, 1994).

Diagnostic Observational Instruments –

- Childhood Autism Rating Scale (Schopler *et al.,* 1988).
- Screening Tool for Autism in Two Year Olds (Stone, 1998a, 1998b).
- Autism Diagnostic Observation Schedule – Generic (Lord *et al.,* 2000).

The Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) and the Autism Diagnostic Observation Schedule – Generic (ADOS-G: Lord *et al.,* 2000) will be outlined as they are currently regarded as the Gold Standards Instruments for the assessment of autism spectrum disorders.

Additional recommendations are outlined in this chapter relevant to the diagnosis of school aged children include (Filipek *et al.,* 2000):

- Medical and Neurological Evaluations.
- Speech, language, and communication evaluation.
- Cognitive and adaptive behaviour evaluations.
- Sensorimotor and occupational therapy evaluations.
- Neurological, behavioural, and academic assessments.

The focus of the present study was to screen school aged children 6-11 years of age for autism spectrum disorder. There are important diagnostic considerations that inform the assessment process for school aged children (Ozonoff *et al.,* 2005):

1. A developmental perspective must be maintained by the clinician (Burack *et al.,* 2002). Autism is a lifelong disorder, first diagnosed in early childhood and continues to be apparent throughout a person's life, characterised by unevenness in development that differs over the lifespan (Mundy, Sigman, Kasari, 1990).
2. The evaluation of a child with Autism should include information from multiple sources e.g. parents, teachers, and clinicians; and in multiple contexts (e.g. in the family home, visiting others, shopping, and school) as symptom severity may be dependent on the characteristics of the child's environment. Measures of cognitive and adaptive behaviour and clinical judgement play an important part in of the multidisciplinary assessment (Filipek *et al.,* 1999).

3. It is recommended that a formal multidisciplinary assessment should include assessment of: social behaviour, language, nonverbal communication, adaptive behaviour, motor skills, atypical behaviours, and cognitive status by a team of professionals experienced in the diagnosis of Autism Spectrum Disorders (Charman & Baird, 2002; Shriver, Allen, & Matthews, 1999).

7.6.2 Review of Child's Developmental History

The first step in the diagnostic process involves a clinician interviewing the child's parents about the child's early developmental history and their current concerns. A critical aspect of the history taking process is to review the child's communication, social and behavioural development, and carry out a brief screening for other potential medical and psychiatric difficulties e.g. anxiety and depression. A review of available records: medical, school, intervention reports should be included in the evaluation process. Teaches should be consulted to provide their observations about child's functioning in the less structured and socially challenging school setting (Ozonoff *et al.,* 2005).

7.6.3 Intellectual Assessment

Level of intellectual functioning is associated with severity of autistic symptoms, ability to acquire skills, and adaptive behaviour (Harris & Handleman, 2000; Lotter, 1974, Rutter, 1984, Stevens *et al.,* 2000). The major goal of cognitive assessments is to generate a profile of the child's strengths and weaknesses to facilitate education planning. IQ is more stable and predictive the older the age at assessment (Lord & Schopler, 1989). IQ scores can increase as a consequence of behavioural interventions (Freeman et al., 1991; Mayes & Calhoun, 2003) increase or decrease as a function of the assessment instrument selected for the evaluation (Magiati & Howlin, 2001).

Children suspected of Autism Spectrum Disorders often present an assessment challenge due to social difficulties, unusual use of language, off task behaviours, high distractibility and variable motivation. When experienced clinicians evaluate children with autism, few should be un-testable. It is important to ensure the test chosen is appropriate for the child's chronological and mental age and provides a full range of standard scores which measure verbal and non-verbal functioning separately (Filipek *et al.,* 1999).

The following scales/tests are among the most commonly used for the assessment of general cognitive ability/developmental level:

- Wechsler Intelligence Scale for Children, 4th Edition (WISC- IV) (Wechsler, 2003).
- Wechsler Pre-School and Primary Scale of Intelligence, 3rd Edition (WIPPSI-III) (Wechsler, 2002).
- Stanford Binet Intelligence Scale, 5th Edition (SB5) (Roid, 2003).
- Griffiths Mental Development Scales (Extended Revised GMDS – ER) (Griffiths, 1996*).*
- British Ability Scales, 2nd Edition (BAS-II) (Elliott, 1996).
- Woodcock-Johnson, 3rd Edition NU Tests of Cognitive Abilities (WJ-III) (woodcock *et al.,* 2001).

7.6.4 Language Assessment

Expressive language assessments and IQ testing are the best predictors of long-term outcome and prognosis (Lotter, 1974; Rutter, 1984; Stone & Yoder, 2001). A variety of instruments listed below have been used to evaluate children for Autism Spectrum Disorders to measure expressive and receptive language abilities. Referral for a comprehensive evaluation by a speech and language pathologist may be required in some instances (Filipek *et al.,* 1999). Children with adequate spoken language who score in the average range on these tests may still exhibit deficits in the use of language in social contexts (Ozonoff *et al.,* 2005).
Tests include:

- Peabody Picture Vocabulary Test – Revised (PPVT-R) (Dunn, 1981)
- Reynell Developmental Language Scales (RDLS (Reynell & Gruber, 1990).
- Clinical Evaluation of Language Fundamentals (Semel, Wiig, Secord, 2003).

7.6.5 Adaptive Functioning Assessment

Evaluation of adaptive behaviour should always accompany intellectual testing, as a diagnosis of mental retardation cannot be made unless functioning is compromised across both standardised tests of intelligence and real life measures of adaptive function. This is important for setting appropriate goals in treatment planning. Children with autism consistently demonstrate adaptive behaviour levels that are lower than their intelligence which is pronounced in children with higher functioning ASDs, with IQs in the normal range (Bolte & Poustka, 2002).

Specific instruments for the assessment of adaptive skills include:

- Vineland Adaptive Behaviour Scales 2nd Edition. (Sparrow *et al.,* 1984)
- Adaptive Behaviour Assessment System 2nd Edition (ABAS-II) (Oakland & Harrison 2008).
- AAMD Adaptive Behaviour Scales (Spreat, 1980).
- Adaptive Behaviour Scale-School-Age: 2nd Edition (ABS-S:II) (Lambert *et al.,* 1993).
- Adaptive Behaviour Scale-Residential and Community: Second Edition (ABS-RC:II) (Kazuo *et al.,* 2011)

7.6.6 Sensorimotor and Occupational Therapy Evaluations

Qualified experienced professional occupational or physical therapists should undertake assessment of: gross and fine motor skills, praxis, sensory motor abilities, unusual or stereotyped mannerisms and the impact of these components on the autistic person's life. An occupational therapy evaluation in indicated when deficits exist in functional skills or occupational performance in the areas of: play or leisure, self-maintenance through activities in daily living, productivity or work tasks (Filipek *et al.,* 2000).

7.6.7 Neuropsychological, Behavioural and Academic Assessments

In addition to cognitive assessment to: include social skills and relationships, education functioning, problematic behaviours, learning style, motivation and reinforcement sensory functioning and self-regulation. Parent's level of understanding of the child's condition, resources and supports should also be assessed in conjunction with appropriate counselling and education (Filipek *et al.,* 2000).

7.6.8 ADOS-G & ADI-R

There is general agreement on the primary characteristics of autism in North American and Europe as evidenced by the close overlap in current diagnostic criteria DSM-IV-R (APA, 2000) and ICD-10 (WHO, 1992) (Sponheim *et al.,* 1996). All professional practice parameters state the necessity for interviewing parents about early development and specific symptoms of autism and observing the child directly (Filipek *et al.,* 1999, 2000; Volkmar *et al.,* 1999).

Particular emphasis will be placed on discussing the use of these instruments Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) and Autism Diagnostic Observation Schedule (ADOS: Lord *et al.,* 2000) in the discussion section given their relevance to the assessment process of autism spectrum disorders. They are considered to be the gold standard instruments for the diagnosis of ASDs (Ozonoff *et al.,* 2005).
These instruments operationally define current DSM-IV (APA, 1994) criteria and separately quantify the three domains that define Autism Spectrum Disorders. This evaluation process can be very helpful in increasing the parents' understanding of the child's disability and setting goals for intervention (Akshoomoff, Corsello, Schmidt, 2006).

7.6.8.1. Parental Interview - Autism Diagnostic Interview – Revised (ADI-R)

The ADI-R (Lord *et al,* 1994) is a semi structured interview designed to differentiate individuals with autism from those with language impairments and mental retardation. The interview can be completed in approx. 2 ½ hours. Questions are scored on the basis of the interviewer's judgement. The ADI-R contains sections on early development, communication, social development, play, repetitive and restricted behaviours, and behaviour problems (Lecavalier, Scahill, McDonald *et al,* 2006). The content of the interview closely mirrors the descriptions of autism from in the DSM IV (APA, 1994) and ICD- 10 (WHO, 1992).

A scoring system has been developed such that children must surpass cut off points in all the ADI-R domains to be diagnosed with autism. Individuals with and without speech have different cut offs on the communication domain and questions can be scored for behavioural difficulties between the ages 4-5 years or at any time during the child's development (Lecavalier, Aman, Scahill, McDougle *et al.,* 2006).

7.6.8.2 Child Observation - Autism Diagnostic Observation Schedule Generic (ADOS-G)

The ADOS-G (Lord *et al.,* 2000) is a semi structured assessment of social interaction, communication, play and imaginative use of materials for individuals who have autism or other pervasive developmental disorders. As part of the schedule, planned social occasions, referred to as "presses" (Lord et al., 1989; Murray, 1938) are created in which a range of social interactions and responses are likely to appear. The goal of the ADOS-G is to provide presses that elicit spontaneous behaviours in standardized contexts (Lord, Risi, Lambrecht, Cook, 2000).

The ADOS-G consists of four modules each one appropriate for children and adults at different developmental and language levels. Only one module, lasting for about 30 minutes is administered to an individual at any given point in time. Expressive language level is possibly the strongest predictor of outcome in autism spectrum disorders, at least in individuals beyond the preschool level (Kobayashi, Murata, & Yoshinaga, 1992 & Venter, Lord, & Schopler, 1992).

The introduction of the different modules in the ADOS-G was intended to minimise the possible biasing effect of variations in language skills by offering different tasks and coding in the appropriate modules. The examiner uses the module that best matches the expressive language skills of the individual child or adult to make judgements about communicative abilities as independent as possible from the effects of absolute level of language delay (Lord, Risi, Lambrecht, Cook, 2000).

The modules provide social-communicative sequences that combine a series of unstructured and structured situations. Each situation provides a hierarchy for presses for particular social behaviours:

- Module 1 - based on the PL-ADOS is intended for children who do not have spontaneous phrase speech.
- Module 2 - for children with some flexible phrase speeches who are not verbally fluent.
- Module 3 - based on the ADOS intended for verbally fluent children for whom play with toys is age appropriate.
- Module 4 - contains the socio emotional questions of the ADOS along with interview items about daily living and additional tasks. The module is intended for fluent adults and for adolescents (usually over 12-16 years).

Administration of the ADOS-G is related to the skill of the examiner and requires practice in administering the activities, scoring, and observations. Examiners are expected to obtain inter rater reliability with experienced clinicians and consensus ratings on videotapes provided by the authors before using the instrument in a clinical setting (Lord, Risi, Lambrecht, Cook, 2000).

7.6.8.3 Combined Use of the Gold Standard Assessment Instruments

The diagnostic reliability and validity of the ADI-R and ADOS has been established by the test developers (LeCouteur *et al.,* 1989; Lord *et al.,* 1994). In comparing the classification accuracy of the ADOS to a consensus clinical diagnosis based on the ADI-R, Lord et al (2000) reported that the ADOS effectively differentiated autism from non autism spectrum disorders (Specificity range:: 0.93 – 1.0) but was less effective at distinguishing autism from PDD-NOS (Specificity range: 0.68 – 0.79).

Bishop & Norbury (2002) reported diagnostic agreement between the ADOS and ADI-R in studies differentiating autism from language impairments. De Bildt *et al.,* (2004) reported that classification agreement between the two instruments was fair, (63.6%) among children and adolescents with mental retardation with greater consensus in younger children.
De Bildt *et al.,* (2004) reported fair agreement between the ADI-R and ADOS-G among children and adolescents with mental retardation with greater consensus reported among younger children.

Tomanik *et al.,* (2007) reported classification agreement of the two instruments for participants with ASD at 7-18 years of age. Linear discriminate analysis revealed adequate concordance with (75%) of participants being correctly classified with the ADOS. Classification accuracy slightly improved to (84%) when a measure of adaptive functioning e.g. Vineland Adaptive Behaviour Scales (VABS: Sparrow et al., 1984) was incorporated into the assessment process. A number of studies have reported poor consensus between these instruments (Bolte & Poustka. 2004; Vontola *et al.,* 2006; Wiggins *et al.,* 2006).

The following child specific characteristics can influence the reliability of these instruments:

- ADI-R is not recommended for use with children who have non-verbal mental ages of 18 months or less or children who are not yet walking (Lord, Storoschuk, Rutter, & Pickles, 1993).
- The sensitivity and specificity of the combined use of the instruments is lower in children under 3 years of age (Cox *et al.,* 1999; LeCouteur *et al.,* 1989).
- de Bildt *et al.,* (2004) found better agreement between the ADI-R and ADOS for children 5-8 yrs of age than for older children and adults.
- Some studies suggest that individuals with mental retardation are over identified as having autism using the ADI-R/ADOS combination (Fombonne *et al.,* 1992).

Clinical consensus has been shown to be more predictive of a stable diagnosis when compared to the strict application of the DSM IV (APA, 1994) (McConachie, LeCouteur & Honey, 2005). The DSM IV criteria are particularly relevant when attempting to differentiate complex psychiatric disorders from autism spectrum disorders (Reaven, Hepburn, Ross, 2008).

In a longitudinal study Lord, Risi, DiLavore *et al.,* (2006) examined the stability of autism spectrum diagnosis at 2 yrs through 9 yrs of age to identify predictors of later diagnosis. Clinical judgement, ADI-R and ADOS all made independent contributions to predicting long term best estimate diagnosis. Percentage agreement between best-estimate diagnoses at 2 and 9 years of age was (67%), with a weighted kappa of (k =0.72). Diagnostic change was primarily accounted for by, movement from PDD-NOS to autism. Each measure at age 2 years was strongly prognostic for autism at age 9 years, with odds ratios of (6.6) for parent interview, (6.8) for observation, and (12.8) for clinical judgment.

7.6.9 The DISCO

The Diagnostic Interview for Social & Communication Disorders (DISCO: Wing, Leekam, Libby *et al.,* 2002) was designed to obtain, systematically, information needed to compile an individual's clinical history from birth and a description of their current clinical picture. The schedule can also be used for research. For this purpose, provisional algorithms have been written. These include three of the sets of standard international diagnostic criteria for pervasive developmental disorders and their sub-groups; DSM-III-R (American Psychiatric Association, 1987), ICD-10 (World Health Organisation, 1992) and DSM-IV (American Psychiatric Association, 1994). The schedule is investigator based; that is, the task of the interviewer is to elicit enough information from the informant to make a judgement as to the most appropriate rating for each item (Wing, Cooper, & Sartorius, 1974).

Instructions for interviewers and suggestions for introductory questions are provided for each item but the wording is not fixed. The questioning has to be adapted in the light of the level of functioning of the child or adult concerned gained from prior information or during the course of the interview. Following the introductory questions the replies determine how the questioning should proceed. Informants are interviewed about past and current behaviour but, apart from a few items concerning developmental skills and any setbacks, the ages when they occurred are not coded. The instructions to the interviewer are to code behaviour that the informant remembers easily and clearly. Ratings should be checked and if necessary changed in the light of information from psychological assessment, structured and unstructured observations of the child or adult concerned, interviews with other informants such as teachers and any available case records. The reasons for any marked discrepancies should be investigated as far as possible (Wing, Leekam, Libby *et al.,* 2002).

7.7 Diagnosis of Autism Spectrum Disorder in Community Settings

Wiggins *et al.,* (2006) examined diagnostic pattern among a sample of 8 year old children identified through the CDC (MADDSP) surveillance programme. The majority of children had not been assigned a clinical diagnosis until entering elementary school. Only (30%) of initial diagnosis had been assigned by clinicians using standardised diagnostic instruments. Rosenberg *et al.,* (2009) reported that Asperger syndrome was less likely to be diagnosed by developmental paediatricians, and more likely to be diagnosed by psychiatrists or clinical psychologists, whereas PDD / ASD was less likely to be diagnosed by clinical psychologists. The authors also found that the proportion of children diagnosed with specific ASD diagnosis changed over time, suggesting secular trends in clinical preference and use of ASD labels.

Daniels *et al.,* (2011) analysed data from a national web based registry to identify factors associated with the stability of community based diagnosis of ASD among children 6 months to 18 years at the time of registration. Twenty two percent of participants had a current diagnosis that was different from their initial diagnosis, consistent with the range of stability estimates reported in past clinical studies (Cederlund *et al.,* 2008; Charman *et al.,* 2005; Chawarska *et al.,* 2007; Kleinman *et al.,* 2008; Lord *et al.,* 2006; Moss *et al.,* 2008; Turner & Stone, 2007).

Determining the stability of initial diagnosis assigned in community setting is important for a number of reasons as outlined by Daniels *et al.,* (2011):

- A lack of stability may be a reflection of poor clinical diagnostic procedures, or a lack of clinician training how to recognise and diagnose the disorder.
- Instability in diagnosis of ASD may reflect variations in clinical practice and use of the ASD label across clinician types and locations.
- Changes in community diagnosis may reflect true changes in the natural history of the disorder.
- Low diagnostic stability may be partly explained whereby clinicians assign either a "placeholder" diagnosis for patients with mild or atypical ASD, particularly those younger than 5 years, waiting to see how the child develops and/or responds to early intervention, thus anticipating label change.

- Children diagnosed around the time of publication of the DSM-IV-R (APA, 2000) may have been reassigned up to several years after the change in diagnostic criteria, depending on how long it took to disseminate the new guidelines.
- Children are been initially diagnosed at a younger age, leading to longer intervals for natural history changes and/or early intervention, which may impact on the final diagnosis assigned.

7.8 Discussion

At present in Ireland the assessment of autism spectrum disorders in conducted in both private practice and public settings. There been no specific protocols developed by the Health Services Executive for the assessment and diagnosis of autism spectrum disorder until the publication of the Psychological Society of Ireland: Special Interests Group: Best Practice Guidelines (2012). Guidelines for the assessment and diagnosis of autism spectrum disorders were first developed by Filipek *et al.,* (1999) (USA). More recent protocols were developed in the United Kingdom: Scottish Intercollegiate Guidelines Network (1997) and more recently by the Institute of Health Clinical Excellence (NICE) draft guidelines were published (2012).

The gold standards instruments ADOS / ADI-R should be included as part of the assessment process (Ozonoff *et al.,* 2005). There are a number of factors which need to be taken into consideration when interpreting the results of these instruments. Scores on the ADI-R for autism are primarily based on the child's developmental history and require retrospective parent recall, introducing a bias for diagnosing older children. Discrepancies are often found between clinical and parental report, for older higher functioning children with adequate adaptive functioning (Norterdaeme *et al.,* 2002).

One of the main difficulties obtaining consensus between the two instruments is that algorithm scores on the ADI-R for autistic disorder are based on exceeding cut off scores in three areas of development (communication, social interaction and restricted interests). The ADOS-G is intended to be one source of information used in making a diagnosis of autism spectrum disorders. Because only a small window of time is considered, the ADOS-G does not offer an adequate opportunity to measure restricted and repetitive behaviours (though such behaviours are coded if they occur).

Thus, ADOS-G algorithms include only items coding social behaviours and communication. Because it consists of codes made from a single observation, the ADOS-G does not include information about history or functioning in other contexts. This means that the ADOS-G alone cannot be used to make complete standard diagnoses historical information, such as provided by the ADI-R is required.

An overall autism diagnosis requires abnormalities in restricted, repetitive behaviours and early manifestations of the disorder. Thus, there may be cases in which an individual receives an ADOS-G classification of autism, but a clinical diagnosis of autism, PDDNOS, or Asperger disorder. Conversely, a clinical diagnosis of PDDNOS may be made in the presence of significant social abnormalities and restricted, repetitive behaviours, without communication dysfunction; in this case, the behaviour of an individual might meet criteria for only the social domain and so not receive an ADOS-G classification of ASD but still receive an overall diagnosis of PDDNOS. These discrepancies illustrate the importance of combining information from the ADOS-G with history and parent report, such as in the ADI-R, and clinical judgment in integrating the information from different sources (Lord, Risi, Lambrecht *et al.,* 2000).

A review of clinical records by Tomanik *et al.,* (2007) reported that many false positive children on the ADOS were described by clinicians as shy, anxious, oppositional or inattentive during the administration process. The false positive rate can be reduced by evaluating children's cognitive and adaptive functioning in conjunction with the ADOS. The mild presentation of core autistic impairments among children with higher functioning autism complicates the differential diagnostic process (Goin-Kochel *et al*., 2006; Holzer *et al.,* 2006; Wiggins et al. 2006). Bishop & Norbury (2002) reported similar observations regarding false positive ADOS diagnosis in children whose cognitive development was in the normal range. There is mixed evidence that the ADOS can differentiate children with Autism Spectrum Disorders from those with specific language impairments. The ADOS may be more effective for differentiating children with pragmatic but not with receptive language impairments (Conti-Ramsden, Simkin & Botting, 2006).

Sikora *et al.,* (2008) evaluated the diagnostic utility of the ADOS-G modules 3 and 4 among children and older adolescents aged 5-21 years of age in distinguishing Autism Spectrum Disorders from other developmental disabilities, 84.9% were correctly classified in the non-spectrum classification.

Children and adolescents with mood and psychiatric disorders had a relatively higher risk of been given a false positive classification on the autism spectrum than those with disruptive behaviours. False positive diagnosis were higher in males but not related to age or cognitive functioning. In addition to the use of the gold standard instruments as part of the evaluation process for autism spectrum disorders cognitive, speech and language, adaptive behaviour assessment are essential components in the diagnosis process which need to be used in conjunction with clinical judgement (Filipek *et al.,* 2000).

The objective of the current study was to validate the use of the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as a primary screening instrument for screening 10,000 children 6-11 years of age for autism spectrum disorders enrolled at national and special education schools in three study regions: Galway, Waterford and Cork in the Republic of Ireland.

CHAPTER 3
STUDY METHODS

1.0 European Protocol for Autism Prevalence (EPAP)

1.1 European Autism Information System (EAIS) project

One of the areas addressed by the European Autism Information System (EAIS: Posada & Ramirez, 2008) project (2006-08) was the lack of systematic, consistent and reliable data about prevalence and trends of ASD in Europe. The project was 60% funded by DG SANCO. In July 2006, a questionnaire was developed for completion by service providers within the EAIS project for improving knowledge about the characteristics of health, education, social or parents' organisations services, devoted to autism, exist in those countries where the European project is being carried out.

The questionnaire focused on the regions (also national information) in which EAIS partners function. The most important conclusions from this survey were:

- It was not clear whether data could be obtained directly from either health or educational services, except in those countries with an active population registry.
- There were many sources that could provide ASD cases.

One objective of the European Autism Information System (EAIS) (Work Package 7.0) was to design a protocol for a study of Autism Spectrum Disorder (ASD) prevalence at European level, called The European Protocol for Autism Prevalence (EPAP). The protocol was developed to facilitate a common format for screening and diagnosing children for autism spectrum disorders across the EU for determining the prevalence of autism spectrum disorders.

1.2 The Screening Criteria

The protocol highlighted the following as been important criteria for inclusion in an prevalence study across Europe:

• A well-defined and delimited geographical and administrative area.
• A stable population (low immigration rate).
• The existence of a Public Health Care System covering near to 100%.
• Accessibility to data from educational and special educational sources.

• Accessibility to the clinical records of the potential cases.
• Rural and urban settings will be considered.

1.3 Population

• The EPAP protocol described the target population as aged 6-11 years of age to facilitate countries where children start school at 6 years of age. In Ireland children start school between 4-5 years of age. The population will be defined by birth year.

1.4 Inclusion criteria

• Children 6-11 years of age during the designated study year, who officially reside in the designated study area during the time of the study.

1.5 Case Ascertainment Procedure

EPAP proposed the following stages:

Stage 1 - Identification of potential cases

• A full inventory of private and public mainstream and special needs schools will be drawn up.
• An inventory of social services for children in the age range selected will be also created.
• School site visits will be conducted and each classroom with pupils aged 6-11 years will be checked through the teachers responsible, who will be interviewed about the children.
The tool for this interview will be a questionnaire – DSM-IV based (Posada *et al.,* 2008 unpublished paper) for this purpose.

• Parents of those children identified by the teacher as possible cases will be asked questions using one of these two questionnaires, the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2005) or the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003).

Stage 2 - First approach to diagnosis

• Parents of those children identified by the teacher as possible cases will be asked questions using one of these two questionnaires.

Stage 3. -Confirmation of the diagnosis

Children with high scores on the SRS or SRS will be referred for (Autism Diagnostic Interview—Revised (ADI-R) and Autism Diagnostic Observation Schedule –Generic (ADOS-G) and multidisciplinary assessment.

• Psychometric tests such as WISC IV and/or K-ABC II for cognitive evaluation and Vineland Adaptive Behaviour Scales (VABS) or may be its second version (VABS-II) for social and communicative evaluation will be also considered to be used.
• The final diagnostic determination will be derived from a review of all existing data by an expert team.

2.0 Irish Autism Prevalence Protocol

2.1 Background

The protocol for the current study was developed based on the European Autism Prevalence Protocol EPAP. On the basis of undertaking pilot studies and collaborating with study partners a number of amendments were made to the case ascertainment phase Stage 1 – (Identification of potential cases) to effectively screen children in mainstream and special education schools which will be discussed in this chapter, please refer to page 19.

2.2 Study Objectives

The objective of the present study was to validate the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as a primary school level screening instrument among a epidemiological population of national and special education school children. The SCQ has been previously validated in clinical settings. The validation study was part of a lager autism prevalence study. A summary of the study stages are outlined below, more detail is supplied in the following sections.

2.3 Project Management, Execution & Completion

Phase I – Protocol Development, and Implementation: (May to Sept 2009)

- Adapt the EPAP protocol (which had not been previously piloted) to effectively screen children for autism spectrum disorder in an Irish context.
- Develop a study booklet for completion by parents of eligible children.
- Selected an appropriate screening instrument.
- Pilot the fieldwork study protocol.
- Identify study regions to screen a representative numbers of children enrolled at national schools (mainstream & disadvantaged) and special education schools in accordance with (EPAP) - 1.2 Setting criteria.
- Contact school principals at national and special education schools in representative study regions of interest inviting participation.
- Sign off on the final format of the study booklet, amendments to study booklet

Phase II – Fieldwork: (Oct 2010 to June 2011)

- Fieldwork undertaken in national and special education schools in three study regions.

Phase III – Identification of Children with Moderate & High Scores on the Screener.

Parent Follow up (July 2011 to Aug 2012)

- Data entry and identification of children with high moderate to high scores on the screening instrument.
- Following up schools requesting summaries of the number of children known to school authorities with established diagnosis on the autism spectrum for the study period of interest.
- Contact the parents of all children who obtained moderate to high scores on the SCQ were contract to re-administer the screening instrument. Parents of children with high to moderate scores were contacted to confirm access to psychological assessments from the child's clinician where he/she was diagnosed.

Phase IV – Clinical Record Abstraction (Sept to Nov 2012)

- Initial mailing to clinicians (July 2012). Meeting clinicians to provide copies of consent forms signed by parents and abstraction of psychological assessments.

2.4 Sample

To screen 10,000 national and special education school children 6-11 years of age (born between 1st January 1998 to 31st December 2003) - birth year was calculated from 1st January 2010.

2.5 Study Design.

A cross sectional design was performed.

2.6 Population

The targeted population was defined as all children enrolled at national and special education schools residing within the designated study regions: Galway, Waterford, and Cork City (south central). Children eligible to participate in the study were 6 to 11 years of age.

2.7 Case Identification

For the purposes of the study, a case was defined as a child who fits the definition of the DSM-IV R (APA, 2000) under the Pervasive Developmental Disorders category codes: F84.0, F84.2, F84.3, F84.5, and F84.9, Autism, Asperger's Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder and PDD-NOS Pervasive Development Disorder - Not Otherwise Specified respectively.

3.0 Study Instruments

3.1 Information Leaflet

An information leaflet was designed to be provided to the parents of all children eligible to participate on the prior to commencing fieldwork (Appendix A).

- Summary of study objectives.
- Explained that all children 6-11 yrs of age born between 1st Jan 1998 to 31st Dec 2003 were eligible to take part in the study, not just children with autism spectrum disorders.
- Parents were asked to contact the study co-coordinator if they required additional information about the study.

3.2 Consent Form

The first page of the study booklet was the consent form which explained:

- The aims and objectives of the study.
- Eligibility criteria – Children 6-11 yrs of age, born between 1st Jan 98 and 31st Dec 03.
- Children who obtained high scores on the screening instrument would be invited to attend further screening.
- Children identified with high scores who attended further assessments and subsequently not diagnosed with an ASD were advised to follow up the outcomes of the assessment with their GP.
- Parent of children with more than one child attending a participating school were asked to complete a study booklet on the child's behalf.
- Requested consent to access school and clinical records for children who had a psychological assessment at the child's school and his/her clinician.

If parents were willing for the eligible child to participate we asked the parent to write the child's name in block capitals, sign the consent form, and provide a contact number. Once the study booklet was completed the child's parent was asked to place the booklet in the study pack provided, to seal it and return it to the child's teacher. It would then be collected by a member of the study team.

Finally parents were informed that we were planning future studies to explore the cause of autism spectrum disorders. The study team requested permission to contact parents at a later stage regarding these studies. Parents who were willing to be contacted were asked to indicate this.

3.3 Study Booklet

The study booklet (Appendix D) was developed for completion by parent and guardians who were the primary care givers for eligible children enrolled in participating schools. Background questions in the study booklet were sourced from three Irish longitudinal studies concerned with child development by kind permission of the authors:

- The Survey of Lifestyle Attitudes and Nutrition in Ireland, Slan: Survey of Lifestyle, Attitudes and Nutrition in Ireland. University College Dublin, School of Public Health & Population Science.
- The Lifeways Study Longitudinal Study – University of Dublin, School of Public Health & Population Science (2001).
- The Growing Up in Ireland – National Longitudinal Study of Ireland: The Lives of 9 year Old Children Economic & Social Research Institute (ESRI) (2009).

Questions included in the study booklet were under the following headings.

- Study child demographics.
- History of developmental difficulties,
- Pregnancy & Birth.
- Post Natal Care.
- Study child siblings.
- Household.
- Parental demographics.
- Social Communication Questionnaire – Lifetime Form (SCQ: Rutter *et al.,* 2003)

3.4 Screening Instruments

The first level screening instrument was the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003), a description of the screen and the psychometric properties were discussed in Chapter 1, Section 5.

3.5 Tracking Logs

Children eligible to participate were given a unique study ID number, which was recorded on the front of the study pack on the top right hand corner of the study booklet. At participating schools the study co-coordinator requested from the school secretary the number of children in each class from senior infants to sixth class eligible to take part in the study. The unique ID numbers were pre-assigned to tracking logs for each class, marked with the teacher's names. Teachers were asked to provide a study pack to each child who was eligible to participate in the study, recording the child's name and date of birth on the tracking log that corresponded with the pack the child received.

4.0 Pilot Study

4.1 Objectives

A pilot study was undertaken at mixed national schools in South County Dublin from February to April 2010 to screen eligible children 6-11 yrs of age for autism spectrum disorder.

The objectives of the pilot were as follows:

- Determine willingness of parents to complete the study booklet.
- Identify problematic questions in the booklet.
- Identify the number of children who obtained Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) cut off scores at or over the recommended cut off ($\geq$15).
- Abstract clinical and school records with parental consent for children who obtained cut off scores ($\geq$15), or who reported a learning disability, including autism spectrum disorder.
- Clinical information abstracted from records was reviewed by a Senior Clinical Psychologist based at Trinity College Dublin to identify children who required ADI-R & ADOS-G assessments.

4.2 Recruitment Procedure

Permission to undertake the pilot studies was requested by principal investigator Dr M.R. Sweeney from school principals. The number of children eligible by class with the teacher's names was requested from school secretaries. Study packs and tracking logs were pre prepared for each class. Prior to commencing fieldwork a meeting was scheduled to meet up with school teachers to explain the aims and objectives of the study and fieldwork protocols. Information leaflets were provided by the study coordinator to teachers for all eligible children prior to undertaking fieldwork which were placed in the children's homework journals for the attention of their parents.

The information leaflet explained that the aim of the study was to screen for autism spectrum disorder, that all children 6-11 years of age would receive a study pack in the coming days for completion by one of their parents to be returned to their teacher for collection by a member of the study team. The study co-coordinator's contact details were provided in the study booklet for parents who required further information about the study.

School principals were asked by the study coordinator if it would be possible to mention in the school newsletter that the school was taking part in the Irish Autism Prevalence Study. The study objectives were outlined emphasizing the significance of participation.

On the Monday of the following week, study booklets were distributed to each class by the study co-coordinator, who confirmed the number of eligible children per class was correct with teachers. Teachers were asked to record on the tracking log (see appendix 3) the name and date of birth for each child who received a study pack and record on the tracking logs which booklets were returned by parents. Teachers were instructed not to open the returned study packs as the child's research ID number was recorded on the front of the study pack.

The 1st reminder letter (R1) (Appendix B) was distributed on the Thursday of the same week to teachers for children who had not returned the study booklet. The reminder letter was placed in the child's homework journal for parent's attention. On the Tuesday of Week 2 (R2) the second reminder letter was distributed, and the booklets were collected again on the Friday of that week. At each stage of the fieldwork tracking logs were checked to keep track of returns, and ensure that the eligible children's' details have been recorded correctly on the tracking logs.

Before commencing fieldwork the study coordinator asked school principals that if the response rates were under 40% prior to giving out the second reminder letter a short text would be sent to parents of all eligible children through the school text system – further emphasizing the significance of participation in the study.

4.3 Screening

The Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) recommended cut off score (≥15) (Berument *et al.,* 1999) was established to identify children at risk of an autism spectrum disorder. Total SCQ scores were calculated in SPSS v17 ™ high scores were also manually checked to ensure they were calculated correctly before contacting parents.
The co-coordinator recorded if the parent expressed concerns about the child's development, if the child had been diagnosed with a learning disability or an autism spectrum disorder.
In the pilot study the parent who completed the study booklet was contact by the study coordinator who explained that their child had obtained a high score on the screener.
The co-coordinator emphasized that the parent should not be concerned as children in the general population can also obtain high scores on the screener who do not have an ASD or other learning disability.

The parent who completed the study booklet was asked if they would be willing for the child to be referred for assessments which would be performed by a research psychologist at based at Trinity College Dublin, Dept of Psychiatry.

These assessments would involve a structured observation of the study child using an instrument called the Autism Diagnostic Observation Schedule-Generic (ADOS-G: Lord *et al.,* 2000) which would be performed at the child's school – approx admin time 45 minutes and a structured interview with the study child's parent who completed the booklet Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) at the parental home – approx admin time 2 ½ hours. Appointments were scheduled for parents to provided written consent for their children to attend the ADOS-G / ADI-R assessments.
Written consent was requested in the study booklet consent form to access psychological assessments from the child's clinician, if any, and their school, through the school principal. Parents were contacted by phone to confirm consent to access these records.

Copies of the consent forms were provided to clinicians and school principals prior to scheduling appointments to access and abstracted relevant clinical information from the child's records relating to:

- Final Diagnosis.
- Date of initial assessment and final diagnosis.
- Clinician involvement in the diagnosis e.g. whether final confirmation was part of multidisciplinary assessment involving speech and language therapists, clinical psychologists, social workers.
- Assessments performed: involved structured testing of cognitive, language and adaptive functioning.

Clinical data was recorded in an encrypted Microsoft Excel ™ worksheet, personal identifiers were not recorded in the file, and children were identified by their unique research ID number.

The following children were referred for ADOS-G & ADI-R assessments with parental written consent:

- SCQ Total Scores ($\geq$15).
- A senior clinical psychologist reviewed clinical data abstracted by the study coordinator from clinical records to identify children for assessment.

4.4 Results

In total (n = 640) children were eligible to participate in the study boys (n = 337), 53%; girls (n = 303), 47%. Response rates were high (n = 463), 72.2% of parents completed the study booklet returned complete boys (n = 239), 51.62% girls (n = 224), 48.38%.

Total SCQ scores were positively skewed 2.64 M = 3.57, SD = 3.72 (SE mean = 0.174), scores were significantly higher for boys M = 40.6, SD = 4.42; girls M = 3.07, SD = 2.75 $t(455)$ $p < 0.0001$. There were no significant differences in SCQ scores by age group.

The scale was extremely reliable $\alpha = 0.891$. The mean, SD, range and confidence intervals are presented in Table 1 for parents of participating children who reported the study child had a diagnosed learning disability, communication or co-ordination disorder.

Table 1: Social Communication Questionnaire Scores for Children with Developmental Disorders in the Pilot Study

Description	N	Mean	SD	Range	95% C Interval	
ASD	4	16.5	8.36	7 - 30	7.73	25.27
Dyspraxia	3	11.14	9.55	3- 30	2.31	19.97
ADHD	4	8.5	6.4	2 - 14	-1.69	18.69
Speech & Language	23	4.55	4.28	0 - 17	2.54	6.56
Slow Progress	21	4.14	2.7	1 - 11	2.91	5.38
No Reported Disorder	401	3.12	2.84	0 - 15	2.84	3.39

Children identified with SCQ $\geq$ 15 n = 8, 1.75% (boys n = 6, 75%; girls n = 2 25%). The boys identified had a prior diagnosis of ASD n = 3, 50%; Dyspraxia n = 2, 33%; speech and language difficulties n = 1, 17%. Two girls were identified: one child with a speech & language disorder, the other had no reported learning disorder. One false positive female (score = 7) was identified with a prior diagnosis of ASD.

School and clinical records were abstracted with parental consent for all children with a diagnosed learning disability who obtained scores ($\geq$15). The SCQ was re-administered to the parents of these children who completed the study booklet by phone.

A summary of the clinical data abstracted were reviewed by Professor. L. Gallagher - TCD, Dept. of Psychiatry. Professor Gallagher recommended that two children should be referred for ADOS-G and ADI-R assessments. The parents of these children agreed to participate in the assessments. There was one boy who had a reported diagnosis of dyspraxia and a girl with a diagnosed speech and language disorder. On completion of these assessments neither child was diagnosed with an autism spectrum disorder.

4.5 Protocol Amendments

The following amendments were made to the EPAP screening protocol developed prior to implementation of the pilot and main studies:

- Teachers were not asked to complete an "ad hoc" DSM-IV based checklist for the identification of children who required screening with the SCQ.
- The SCQ was completed by all children eligible to participate in the study, which was included in the study booklet.

4.6 Study Booklet Amendments

On completion of the pilot study the following amendments were made to the study booklet:

- The Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) was moved from the end to the middle of the booklet. The screener was moved to reduce the risk of fatigue effects on completion of the instrument.
- The Strength and Difficulties Questionnaire (SDQ: Goodman, 2000) was removed from the study booklet. Although it could have provided useful background information which could have been used in conjunction with the screen with respect to the identification of children at risk of conduct-oppositional disorders, hyperactivity-inattention disorders, and anxiety disorders which are recognised co-occurring with autism spectrum disorders.
- The length of the study booklet was an issue, had the SDQ remained in the booklet, although more comprehensive information would have been collected for the population screened, response rates might have been reduced considerably.
- A few short questions related to the mothers pregnancy and breast feeding practices sourced from the SLAN (2007) study were added to the study booklet.

5.0 Fieldwork Protocol

5.1 Identification of Schools in Study Regions

Irish Department of Education primary school enrolment data was downloaded for national and special education schools from the website:

http://www.education.ie/en/Publications/Statistics/Data-on-Individual-Schools/

Potential study regions were identified base on the following criteria:

- All eligible children enrolled in national and special education schools could be screened. This was an important consideration given the limited resources and constraints for screening children by the end of school term June 2011.
- There was a mix of mainstream and disadvantaged (DEIS I II) schools in the selected regions. Availability of social and medical services in the selected study regions.
- Consultation and final agreement with study principal investigators.

A breakdown of the number of children enrolled at national and special education schools in the three selected study regions is provided in Table 2 – for children enrolled in senior infants, 1st and 6th class eligible to take part in the study.

Due to resource limitations for screening schools in Cork (South Central) we were unable to invite all 27 schools to participate in the study – only a sample of 11 schools were invited and gave consent to participate in the study.

Table 2: Children Enrolled at National Schools Study Regions (Galway, Waterford, and Cork City, South Central) Source: Dept. of Education, Ireland

		Boys		Girls		Total	
Study Region	Schools (n)	n	%	N	%	N	%
Galway City	23	3518	51.20%	3353	48.80%	6871	100.00%
Waterford City	21	2093	51.10%	2971	48.99%	6064	100.00%
Cork (South Central)	27	3322	43.00%	4404	57.00%	7726	100.00%

The number of children enrolled in special education schools in the three study regions is presented in Table 3. The Dept. of Education data sourced from the website was only preliminary data. Not all children were eligible to take part, especially in special education schools that cater for children from 6 -18 years of age. Meetings were scheduled to meet up with school principals to invite participation which will be discussed. The number of children eligible to participate in the study was requested from the schools which agreed to take part.

Table 3: Children Enrolled in Special Education Schools in the Three Study Regions: Source Dept of Education, Ireland

		Boys		Girls		Total	
Study Region	Schools (n)	n	%	N	%	N	%
Galway City	5	100	68.49%	46	31.51%	146	100.00%
Waterford City	2	94	62.67%	56	37.33%	150	100.00%
Cork (South Central)	4	88	57.89%	64	42.11%	152	100.00%

5.2 Inviting National & Special Education Schools to Participate

Invitation letters were posted to national and special education school in the three study regions addressed for the attention of the school principal. The letter stated the aims and objectives of the study, outlining why the study regions were selected. School principals who were willing for their school to take part in the study were asked to sign and return a consent slip at the bottom of the invitation letter to the study coordinator based at Dublin City University, School of Nursing.

The majority of schools did not respond to the letter, follow up calls were made two weeks after posting the invitation letters to schedule meetings with the school principals to explain the study fieldwork and screening protocols in depth, significance of participation and request permission to participate in the study. These meetings with school principals were undertaken at Waterford and Galway schools from April to June 2009 and in Cork (South Central) from February to March 2010.

A breakdown of national schools that agreed and refused to take part in the study is provided in - Table 4.The primary reason provided by school principals for non participation was their involvement in Dept. of Education studies at the time which involved parental participation. All special Education schools contacted in the three study regions: Galway n = 5, Waterford n = 2, and Cork (South Central) n = 4 agreed to participate.

Table 4: National Schools, Agreed & Refused to Participate.

	Agreed to Participate		Refused to Participate		Total	
Study Region	N	%	N	%	n	%
Galway City	15	65.22%	8	34.78%	23	100.00%
Waterford City	18	85.71%	3	14.29%	21	100.00%
Cork (South Central)	7	63.64%	4	36.36%	11	100.00%

5.3 Fieldwork in the School Setting

The fieldwork protocol has been previously described in Section 3.2 - *Recruitment Procedure for the pilot study*: The following amendments were made to the fieldwork and screening protocols for the main study:

- Separate consent was not requested parents to access psychological assessments from clinicians and schools as written consent to access these records was requested in the study booklet consent form, verbal consent was verified prior to contacting clinicians.
- Interviewers were recruited to make initial contact with the parents of children who completed the study booklet to follow up whose that obtained: high, moderate and scores in the normal range.
- Before commencing fieldwork at national and special education schools in Galway and Waterford local media were contacted to inform parents about the study.

A website for the study www.autismcounts.eu was developed, information about the study relevant to parents and teachers was provided relating the fieldwork, screening procedures and the assessment protocols for further screening. Information about the website was provided on the information leaflet which was distributed before starting fieldwork and on the consent form of the study booklet.

Before undertaking fieldwork local newspapers in study regions were contacted to generate awareness about the study. Fieldwork was undertaken at schools in Galway: from November to December 2010; and in Waterford and Cork from March to June 2011.

A breakdown of the number of children eligible to participate at schools who agreed to take part in the study was requested from school secretaries, and is provided in Table 5.
In total of n = 7951 children were eligible to participate from national (males n = 4186, 51.97%; females n = 3869, 48.03%) and from special education schools n = 186, 2.26%.

Table 5: National School Population Eligible to Participate, Source: Dept of Education, Ireland

	National Schools							
	Mainstream		Disadvantaged		Special Ed		Totals	
Study Region	n	%	N	%	N	%	N	%
Galway City	1630	57.54%	1143	40.35%	60	2.12%	2833	100.00%
Waterford City	2095	57.49%	1496	41.05%	53	1.45%	3644	100.00%
Cork City	1587	95.43%	0	0.00%	76	4.57%	1663	100.00%

5.4 Following up of Non Responders

Parents of children with language and literacy issues, or at possible risk of a social, communication or coordination disorders whose parents did not complete a study booklet were identified and followed up through home school liaison officers at disadvantaged schools in Galway and Waterford. Mainstream schools in the Irish Republic do not employ home school liaison officers. With the permission of the school principals, liaison officers attempted to follow up the parents of these children, to help them to complete the study booklet on behalf of the eligible child.

Two strategies were implemented by home school liaison officers to follow up these children:

- The study booklet was sent out again to the parents with a brief note requesting completion by the child's parent on behalf of the eligible child.
- The home school liaison officer contacted the child's parent who completed the booklet (usually the child mother) to schedule an appointment for the parent to complete the booklet with their assistance.

6.0 Screening Protocol

6.1 Identification of Children with High Scores on the Screener

The objective of undertaking follow up screening was to identify children who obtained high scores on the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) at the cut off score, 15 and over, as recommended by (Berument *et al.,* 1999). To reduce the risk of missing children who obtained sub threshold scores, all children who obtained scores in the 12-14 range were also followed up.

Parents of children who scored in the moderate (12-14) and high score range (15+) were contacted by phone. The parent who originally completed the study booklet was asked if they were willing to recomplete the SCQ for the study child that was posted to their residential address for completion and return to the study team in a self-addressed envelope, postage paid.

The Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) has not been used in previous research studies to screen children in the general population for autism spectrum disorder.

A validation study was undertaken to screen a representative sample of eligible children who had obtained scores in the normal range (<12). A random sample of children who scored in normal range, stratified by age, gender, nationality (Irish/Non Irish) and school type (mainstream/disadvantaged) were followed up.

Six experienced public health researchers, based at DCU School of Nursing were recruited to follow up the parents of these children (n = 755) see Table 6, to re-administer the SCQ with the objective of identifying children who required ADOS-G/ADI-R assessments and determining the temporal stability of the screen.

Table 6: National School Children Identified and Followed up for Further Screening in the Main Study

Cut off Score	N	%
12-14 (Borderline)	225	4%
15 + (At Risk)	230	4%
< 12 (Normal Range)	300	6%
Totals	755	

6.2 Interviewer Training

Interviewer training was undertaken at the School of Nursing – November 2011 by the study co-ordinator and principal investigator Dr M.R. Sweeney. The following documents were distributed to interviewers before commencing the first training session:

- Code of practice.
- A list of frequently asked questions about the study.
- Quota sheets.
- Procedure manuals.
- Follow up lists.
- Cover letters for parents explaining the follow up protocol.
- The Social Communication Questionnaires (SCQ) re-administration.

The training session was undertaken over two days, interviewers were familiarised with the study documents and follow up procedures. Mock interviewers were undertaken before commencing follow up calls which were supervised by Dr Sweeney for feedback. Follow up interviewers were undertaken from November 2011 to March 2012 to evaluate interviewer competency.

6.3 Follow up Procedure

Interviewers were instructed in the follow up procedure manuals to contact the parent who completed the study booklet by phone, identify themselves as a researcher based at Dublin City University, School of Nursing working on the Irish Autism Prevalence Study. Interviewers explained to the parent who completed the study booklet that the study team were following up parents of children who obtained high scores and scores in the normal range to request the parent's permission to post a copy of the screener which was originally included in the study booklet for re-completion to compare scores over time.

The screener was posted to parents, for return in a self-addressed envelope to the interviewer postage paid. Arrangements were in place with the administration staff at the School of Nursing to keep screener returns (which had distinct envelopes with the funder's logo) in a separate location to other incoming mail for collection by interviewers. Progress reports were scheduled on a fortnightly basis with the study coordinator, Dr M.R. Sweeney and the interviewers to discuss: return rates, interviewer queries and general feedback from parents.

6.4 Abstraction of Psychological Assessments

The study coordinator contacted parents of children who reported the study child had a diagnosed learning disability (including autism spectrum disorder) who obtained SCQ scores in the moderate and high score range to verify consent to access psychological assessments. Letters were posted to clinicians outlining the study objectives and notifying them they would be provided with the identities of children requesting in the coming weeks requesting access to their psychological assessments.

The following clinical data was abstracted:

- Confirmation of primary diagnosis and secondary conditions.
- Diagnostic criteria.
- Date of diagnosis.

If the child had a diagnosis on the autism spectrum a summary of the following psychometric instruments was abstracted:

- Cognitive.
- Occupational therapy.
- ADOS / ADI-R.

6.5 Identification of the "At Risk" Cohort for Referral

A specific protocol was developed with the study funding body to follow up children who obtained high to moderate scores on the Social Communication Questionnaire:

- Reported the child did not have a diagnosed learning disability (Inc autism spectrum disorder)
- Awaiting consultation for assessment.
- Abstraction of psychological assessments was inconclusive in terms of verifying parent reported diagnosed disorders.
- Parents of study children with and without a diagnosed learning disability (Inc autism spectrum disorder) who had concerns regarding autism spectrum disorder.

6.6 Validation Study

A validation study was undertaken among a random sample of (n = 300), 6% of children who obtained SCQ scores in the normal range. The random sample was generated from normal scoring children stratified by age, gender, class, and school type.

CHAPTER 4
SCHOOL RESPONSE RATES & PARTICIPANT SOCIO-DEMOGRAPHICS NATIONAL SCHOOLS

1.0 School Response Rates

1.1 Introduction

The objective of this chapter is to outline the number of children who were enrolled at national schools by school type (mainstream vs. disadvantaged) and class. Response rates from parents who completed study booklets will be explored by school type, class, and for study child's age and gender. The social demographic characteristics of the primary care giver who completed the majority of study booklets (mothers) will be described with respect to their:

- Social Classification.
- Place of Residence.
- Nationality.
- Level of Education.
- Employment Status.
- Ethnic & Cultural Background.

Waiting times for a diagnosis and parental awareness of problems in development and behaviour will be explored for children identified with diagnosed developmental disorders. The characteristics of these children will analysed in greater detail in the proceeding chapters.

1.2 Screening at National Schools

There were (n = 7951) children screened enrolled in classes 1st to 6th, including special education units at national schools, males 54% (n = 4268) females 46% (n = 3683). An equal number of children were screened at two types of national schools, mainstream and disadvantaged schools see Table 7.

Table 7: Children Screened at Disadvantaged (DEIS) and Mainstream National Schools

School Type	Males		Females		Totals	
	N	%	N	%	N	%
DEIS	1534	58.13%	1105	41.87%	2639	100.00%
Mainstream	2734	51.47%	2578	48.53%	5312	100.00%

There were only marginally significant differences observed by gender and class with slightly higher enrolment rates for males for children enrolled in 1st to 6th class ($\chi 2$ (5) = 11.245, p = 0.046), see Table 8.

Table 8: Children Enrolled at National Schools 1st to 6th Class Screened by Gender and Class

Class	Males		Females		Totals	
	N	%	n	%	N	%
1st Class	531	56.55%	408	43.45%	939	100.00%
2nd Class	839	54.30%	706	45.70%	1545	100.00%
3rd Class	767	51.55%	721	48.45%	1488	100.00%
4th Class	746	55.06%	609	44.94%	1355	100.00%
5th Class	699	54.14%	592	45.86%	1291	100.00%
6th Class	658	50.89%	635	49.11%	1293	100.00%

1.3 Parent Response Rates at National Schools

1.3.1. School Type Differences in Response Rates

Overall return rates were (n = 5589) 69%, (5457 less n = 132 cases excluded - Incomplete data). The majority of study booklet returns were from mainstream schools 71% (n = 3837) with almost an equal rate of returns by gender: males 49% (n = 1877) females 51% (n = 1960). The majority of returns at disadvantaged schools were for males 74% (n = 1178).

1.3.2 Gender x Class Differences in Response Rates

Significant differences in study booklet returns were observed by gender and class ($\chi 2$ (5) = 13,475, p = 0.019).

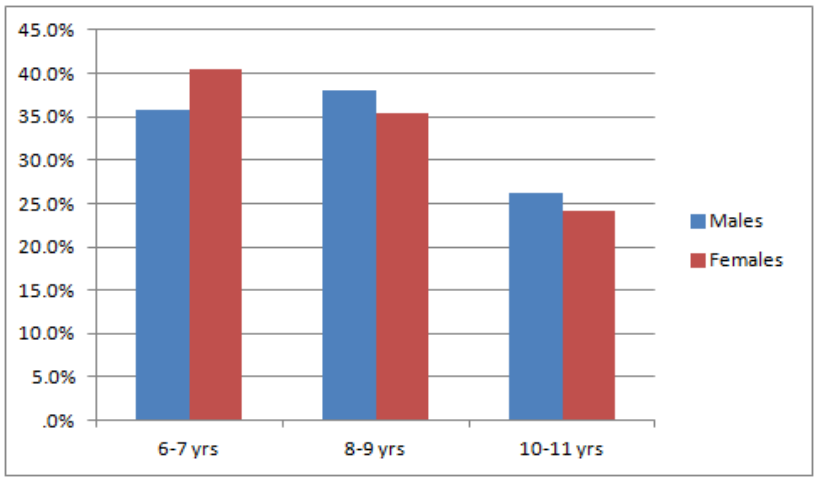
Table 9: Parental Response Rates for National Schools by Gender and Class

	Males		Females		Totals	
Class	N	%	N	%	N	%
1st Class	372	12.20%	336	14.10%	708	13.00%
2nd Class	533	17.40%	477	20.10%	1010	18.60%
3rd Class	641	21.00%	474	19.90%	1115	20.50%
4th Class	538	17.60%	386	16.20%	924	17.00%
5th Class	526	17.20%	370	15.60%	896	16.50%
6th Class	445	14.60%	335	14.10%	780	14.40%
Totals	3055	100.00%	2378	100.00%	5433	100.00%

1.3.3 Age Differences in Response Rates

There were significant differences in the percentage of study booklet returns by age group and gender ($\chi 2$ (2) = 12.898, p = 0.002). Returns rates were highest for females in the 6-7 age group 40.5% (n = 965) for males return rates were highest in the 8-9 year group 38% (n = 1169).

Figure 1: Response Rates for National School Children by Age x Gender



2.0 The Study Child's Primary Care Givers

2.1 Informants

The majority of parents who completed the study booklet provided most care for the study child since birth 98% (n = 5137). Study booklets were primarily completed by mothers 86% (n = 4474), only a small proportion of booklets were completed by fathers 7% (n = 342), or both parents 6% (n = 343).

2.2 Place of Residence

Sixty six percent (n = 3563) of study children were reported as living with both parents followed by those living with lone mothers 30% (n = 1633), 1% (n = 52) were residing with lone fathers.

2.3 Marital Status

Parents reported marital status reported as follows: married 72% (n = 3829), single 13% (n = 706), co-habiting 7% (n = 385), separated or divorced 7% (n = 404), widowed 1% (n = 52).

2.4 Socio Economic Characteristics

The study child's parent who completed the study booklet was asked to provide socio-economic information for both the mother and father, even if the study child was not residing with both parents at the time of the study. The socio-economic status for the study child parents will be discussed with respect to:

- Social Classification.
- Place of Residence.
- Nationality.
- Level of Education.
- Ethnic & Cultural Background.

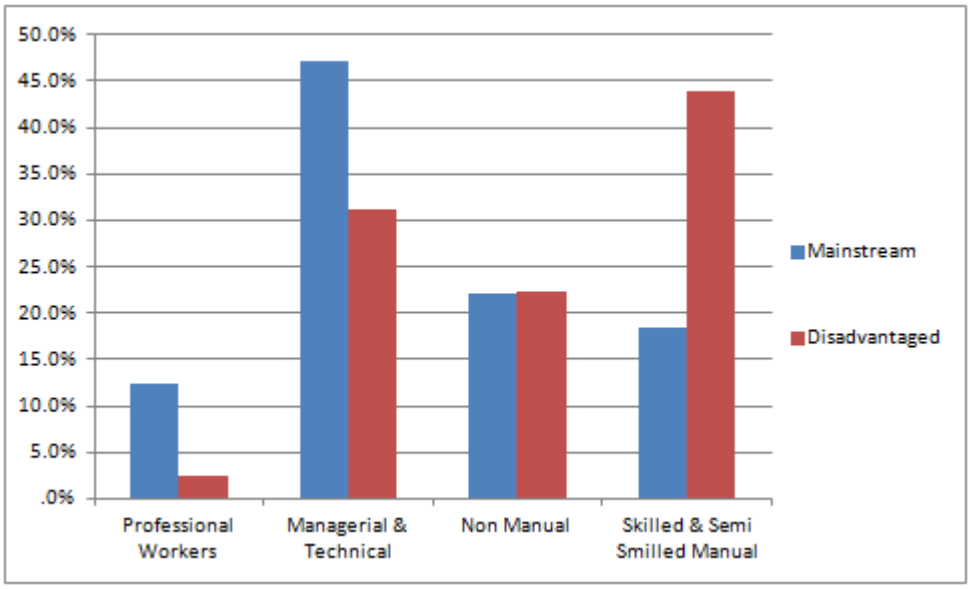
Emphasis will be placed on presenting and analysing findings for the parent (mother) who completed the majority of study booklets on the study child's behalf.

2.4.1. Social Classification

Social class was classified using the Central Statistics Office (CSO) Irish Census 2006 classification criteria. Sixty two percent (n = 3236) of mothers reported they were employees or self-employed, looking after the family home 24% (n = 1287) unemployed or on a state training scheme 7% (n = 386). The majority of mothers in employment at the time of the study were working in managerial or technical positions followed by those employed in skilled and semi-skilled manual occupations, only 10% (n = 320) of mothers were classified as professional workers.

Fifty nine percent (n = 1434) of mothers employed in professional and managerial technical occupations study children attended a mainstream school, compared with disadvantaged schools (n = 275, 33.5%) ($\chi 2$ (3) = 259.836, $p < 0.001$), see Figure 2.

Figure 2: Mothers Social Class for National School Children



Seventeen percent (n = 785) of fathers reported they were unemployed or on a state training scheme. Working fathers were primarily employed in skilled and semi-skilled manual occupations, followed by those working in managerial and technical positions see Table 10.

Table 10: Social Classification Groupings for National School Study Children's Fathers

Social Class	N	%
Professional Workers	659	16.10
Managerial & Technical	1074	26.25
Non Manual	314	7.67
Skilled & Semi Skilled Manual	2045	49.98
Total	4092	100.00%

2.4.2 Place of Residence

Sixty two percent (n = 2640) of households were reported to be owner occupied with or without mortgage. Eighty five percent (n = 271) of professional working mothers reported their household was owner occupied (with /without mortgage) compared to 53% (n = 420) classified as skilled and semi-skilled manual workers ($\chi 2$ (9) = 271.679, $p < 0.001$).

2.4.3 Nationality

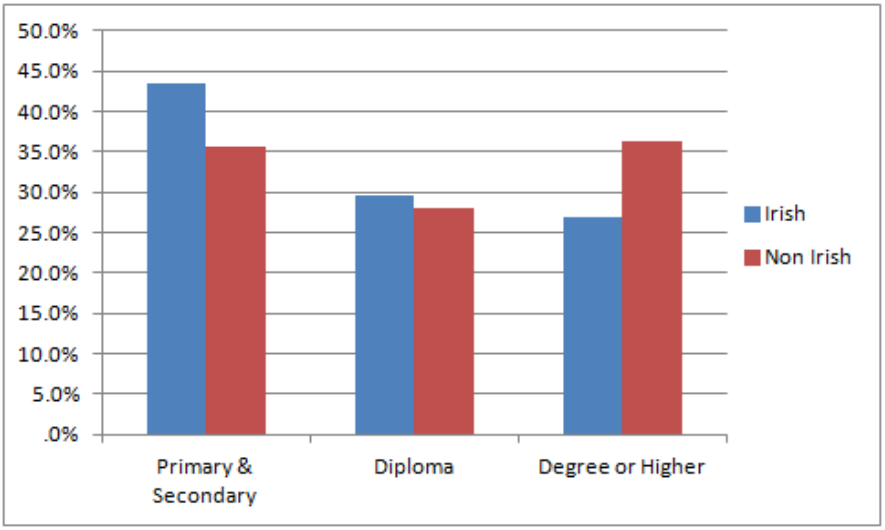
Thirteen percent (n = 733) of study children; males 14% (n = 416) and females 13% (n = 317) were born outside of Ireland. Twenty four percent (n = 1221) of study children's mothers reported they were not born in Ireland. Seventy seven percent (n = 1837) of Irish born mothers were working in non-manual occupations, compared with 66% (n = 471) of non Irish born mothers ($\chi 2$ (3) = 45.972, $p < 0.001$).

2.4.4 Level of Education

Significant differences were observed by mother's level of education and social class ($\chi 2$ (6) = 1042.357, $p < 0.001$). Ninety six percent (n = 302) of mothers in the social classification "professional workers" reporting been educated to degree and postgraduate level compared with 11% (n = 89) mothers working in skilled and semi skilled manual occupations. Twenty seven percent (n = 1013) of Irish born mothers reported been educated to degree level and higher compared with 36% (n = 435) of non Irish born mothers ($\chi 2$ (2) = 42.742, $p < 0.001$).

However only 15% (n = 225) of mothers with children enrolled at disadvantaged schools were educated to degree level or higher, compared with 35% (n = 1293) of mothers with children enrolled at mainstream schools.

Figure 3: Mothers Nationality & Level of Education for National School Children



2.4.5 Ethnic or Cultural Background

As expected the majority of mothers described their ethnic or cultural background as Irish 81% (n = 3999), with 11% (n = 528) describing their background as Irish Traveller other white background, 6% (n = 301) of mothers reported they were African or other black background and 3% (n = 130) reported they were Asian background.

3.0 Learning, Communication & Co-ordination Disorders

3.1 Parent Reported Disorders

Thirteen percent (n = 694) of participating children's primary caregivers reported learning, communication or co-ordination disorders which were diagnosed 59% (n = 411), undiagnosed 35% (n = 245) and pending consultation 5% (n = 38).

A breakdown of children in these groups by gender is provided in Table 11, a higher percentage of males were represented in the three groups.

Table 11: Parent Reported Developmental Disorders by National School Study Children's Diagnostic Status

	Males		Females		Totals	
Diagnostic Status	N	%	N	%	N	%
Diagnosed	293	71.29%	118	28.71%	411	100.00%
Undiagnosed	156	63.67%	89	36.33%	245	100.00%
Pending Consolation	23	60.53%	15	39.47%	38	100.00%

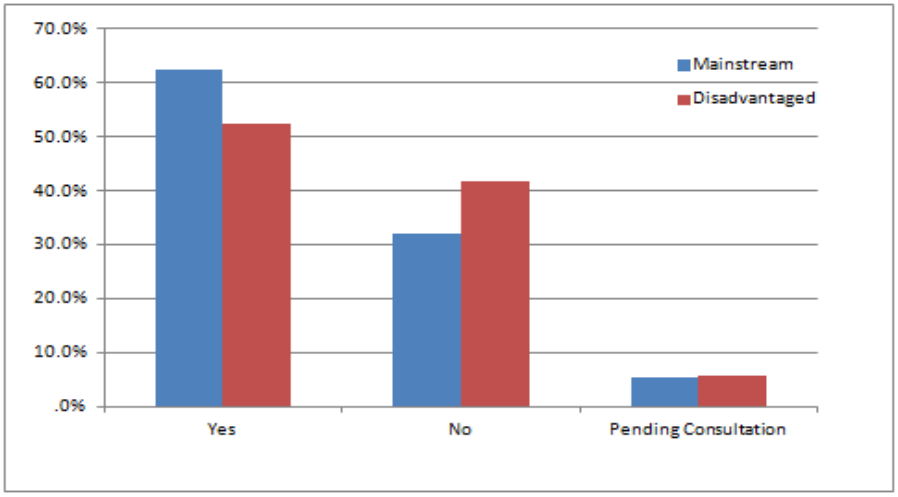
3.2 National School Children's Diagnostic Status

Chi square tests were performed to explore if there were significant differences in diagnostic status (diagnosed, undiagnosed, and awaiting consultation) of participating children with respect to the following variables:

- Age
- Gender
- School Type.

Significant differences were not observed by gender ($\chi 2$ (3) = 5.128, p > 0.05) or age group ($\chi 2$ (4) = 6.885, p > 0.05). Marginally significant differences were observed by the type of school attended by the study child ($\chi 2$ (2) = 6.769, p = 0.034). Sixty two percent (n = 292) of parents of children enrolled at mainstream schools reported the study child had received a professional diagnosis compared with 52% (n = 119) of children enrolled at disadvantaged school see Figure 4.

Figure 4: Diagnostic Status & School Type for National School Children



Chi square tests were also performed to explore if there were significant differences in study children's diagnostic status and the mothers socio-economic characteristics:

- Social Classification.
- Level of Education.
- Ethnic & Cultural Background.
- Nationality (Irish/Non Irish).

Statistically significant differences were not observed for the study child's mothers social class ($\chi 2$ (6) = 8.695, p > 0.05), level of education ($\chi 2$ (4) = 4.717, p > 0.05), ethnic or cultural background ($\chi 2$ (6) = 9.995, p > 0.05) or nationality ($\chi 2$ (4) = 6.657, p > 0.05).

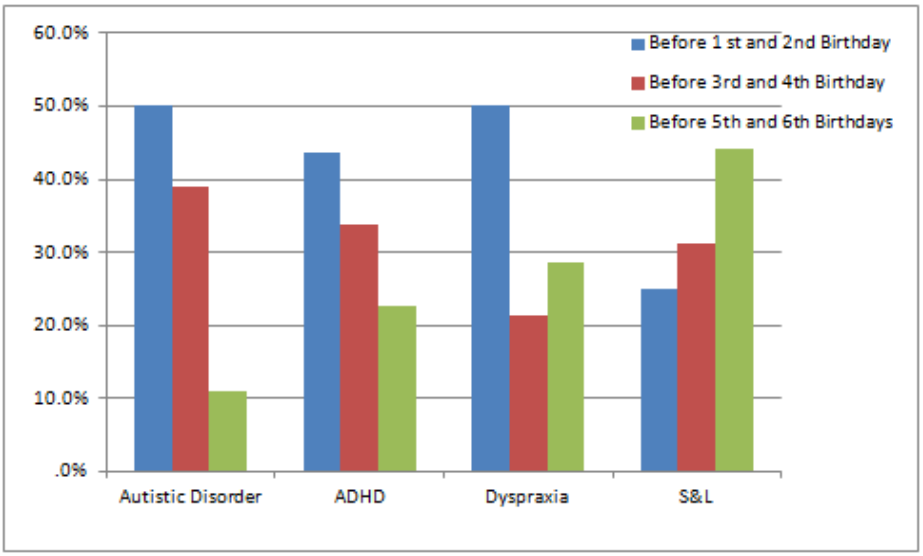
3.3 National School Children's Waiting Times for a Formal Diagnosis

Waiting times for the study child to receive a formal diagnosis were not significantly different by study child's age, gender, type school attended, type of diagnosed disorder, or the mother's: ethnic or cultural background, nationality, social class or level of education.

3.4 National School Children's Difficulties in Development & Behaviour

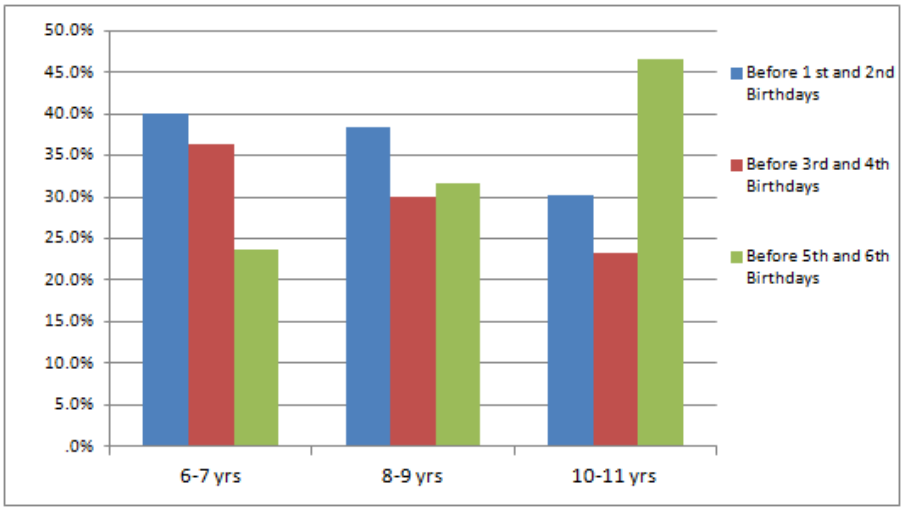
There were statistically significant differences when parents were first aware of problems in the study child's development for different diagnosed developmental disorders. Overall sixty six percent (n = 234) of parents expressed concerns before his/her fourth birthday.
Early recognition of the study child's developmental difficulties was highest among parents of children with a diagnosis of ASD 89% (n = 48) Dyspraxia 77% (n = 48) and ADHD 71% (n = 30). This is an important finding given that almost ½ of the questions in the Social Communication Questionnaire (SCQ) related to the child's development at 4-5 years of age, see Figure 5.

Figure 5: National School Children who First Showed Problems or Difficulties in Development or Behaviour with Diagnosed Disorders.



Significant differences were not observed when parents were aware of difficulties in development and behaviour by the child's gender ($\chi 2$ (2) = 1.766, p > 0.05), significant differences were observed by age group ($\chi 2$ (4) = 13.954, p = 0.007) whereby a higher percentage of mothers of younger children were aware of problems compared to the parents of older children, see Figure 6.

Figure 6: Parental Awareness of National School Study Children's Developmental Difficulties by Age Group



Significant differences were not observed for in awareness of developmental difficulties and the mothers level of education ($\chi 2$ (4) = 1.811, p > 0.05) or social class ($\chi 2$ (6) = 5.825, p > 0.05) or ethnic or cultural background ($\chi 2$ (6) = 9.124, p > 0.05) or for the mothers nationality ($\chi 2$ (4) = 4.808, p > 0.05).

3.5 Discussion

Response rates from parents were high (~70%) at participating schools. The majority of returns were from mainstream schools (71%) with almost equal return rates by gender, an equal return rate was not observed at disadvantaged schools, 74% of returns were for males. This discrepancy in returns cannot be explained given that an equal number of children were screened at both types of national school.

The majority of study booklets were completed by Irish married mothers, employed in managerial and technical occupations. Fifteen percent of mother with children enrolled at disadvantaged schools were educated to degree level or higher compared with 35% of others of children enrolled at mainstream schools.

Parental literacy, language issues, and level of education are likely to have been contributing factors resulting in low response rates at disadvantaged schools. Home school liaison officers at these schools assisted a number of African and Polish mothers with poor English (these children were predominately boys) to complete the booklets for children eligible to participate in the study known to teachers with learning difficulties (including autism spectrum disorders) or suspected of having undiagnosed communication, social and other developmental disorders.

The poorest study booklet return rates were from parents of children in 1st and 5th and 6th classes. The low response in first class may reflect concerns of some parents regarding the development of young children. On the other hand low response rates among parents in higher grades may reflect that parents did not consider the study to be relevant to their child if they had not come to the attention of teachers in the formative school years as presenting with difficulties. There was a higher percentage of study booklet returns for girls in the youngest age group 6-7 years, but a greater percentage of returns of boys in the other two age groups, 6-7 yrs and 10-11 years of age.

Fifty nine percent of parents reported study children's learning, communication or co-ordination difficulties were diagnosed. The majority of these children were of male gender. A significantly higher percentage of children enrolled at mainstream schools had received a diagnosis when fieldwork was undertaken.

There were no significant differences in the percentage of children with a diagnosis, undiagnosed and awaiting consultation by age group, gender, or for the mother's level of education, ethnic or cultural background, social class or nationality.

The majority of parents with a study children diagnosed on the autism spectrum reported that they were aware of problems in the child's development or behaviour prior to his/her fourth birthday, awareness of developmental difficulties was also reported by parents of children with a diagnosis of ADHD and dyspraxia. This is important given that almost ½ of the questions in the SCQ relate to the child's development when he/she was 4-5 years of age. Significant differences were not observed relating to awareness of developmental difficulties and study child's gender, a greater percentage of parents of children 6-9 years of age were aware of developmental difficulties compared with older children 10-11 years of age. There were no significant differences in awareness of developmental problems for mothers of different levels of education, ethnic or cultural background, social class or nationality.

Table 12: Study Children's Demographic Characteristics for the National School Population – Part I

National School Sample					
	Autism Counts		**Dept of Education**		
	N	%	N	%	+ / -
Age (Yrs)					
6 – 7	2,048.00	37.70%	124,247.00	36.67%	8.51%
8 – 9	2,006.00	36.93%	119,579.00	35.29%	-2.61%
10 – 11	1,378.00	25.37%	94,988.00	28.04%	-5.90%
Totals	*5,433.00*	*100.00%*	*338,814.00*	*100.00%*	
Gender					
Males	3,055.00	56.23%	173,181.00	51.11%	-5.12%
Females	2,378.00	43.77%	165,633.00	48.89%	5.12%
Totals	*5,433.00*	*100.00%*	*338,814.00*	*100.00%*	
Class					
1st Class	708	13.03%	39,410.00	11.63%	-1.40%
2nd Class	1,010.00	18.59%	62,399.00	18.42%	-0.17%
3rd Class	1,115.00	20.52%	61,487.00	18.15%	-2.37%
4th Class	924	17.01%	59,604.00	17.59%	0.58%
5th Class	896	16.49%	58,521.00	17.27%	0.78%
6th Class	780	14.36%	57,393.00	16.94%	2.58%
Totals	*5,433.00*	*100.00%*	*338,814.00*	*100.00%*	
School Type					
Mainstream	3,837.00	70.62%	273,630.00	80.76%	10.14%
					-
Disadvantaged	1,596.00	29.38%	65,184.00	19.24%	10.14%
Totals	*5,433.00*	*100.00%*	*338,814.00*	*100.00%*	

Table 13: Study Children's Demographic Characteristics for the National School Population – Part II

National School Sample		
	N	%
Nationality		
Irish	4,700.00	86.51%
Non Irish	733	13.49%
Totals	*5,433.00*	*100.00%*
Place of Birth		
Irish	4,700.00	86.51%
Western European	353	6.50%
Eastern European	72	1.33%
Asian	130	2.39%
African	79	1.45%
American / Canadian	68	1.25%
Other Countries	31	0.57%

Table 14: Study Children's Mothers Demographic Characteristics for the National School Sample

National School Sample		
	N	%
Marital Status		
Single	706	13.13%
Co-Habiting	385	7.16%
Married	3829	71.22%
Separated, Divorced	404	7.51%
Widowed	52	0.97%
Totals	*5376*	100.00%
Employment Status		
Employee	*2940*	56.54%
Self Employed, Farmers	*296*	5.69%
Student's	*162*	3.12%
Unemployed, On State Training Scheme	*386*	7.42%
Long Term Illness, Disability	*120*	2.31%
Looking after the Home	*1287*	24.75%
Retired	*9*	0.17%
Totals	*5200*	100.00%
Level of Education		
Primary, Secondary	2187	41.94%
Certificate, Diploma	1519	29.13%
Degree or Higher	1508	28.92%
Totals	*5214*	*100.00%*
Social Class		
Professional Workers	320	9.90%
Managerial & Technical	1389	42.98%
Non Manual	719	22.25%
Skilled & Semi Skilled Manual	804	24.88%
Totals	*3232*	*100.00%*
Ethic or Cultural Background		
Irish	3984	*80.71%*
Irish Traveller, Other White Background	526	*10.66%*
African, Other Black Background	298	*6.04%*
Chinese, Other Asian Background	128	*2.59%*
Totals	*4936*	*100.00%*

Table 15: Study Children's Fathers Demographic Characteristics for the National School Sample

National School Sample		
	N	%
Employment Status		
Employee	*2679*	58.35%
Self Employed, Farmers	*913*	19.89%
Student's	*56*	1.22%
Unemployed, On State Training Scheme	*785*	17.10%
Long Term Illness, Disability	*93*	2.03%
Looking after the Home	*53*	1.15%
Retired	*12*	0.26%
Totals	*4591*	100.00%
Level of Education		
Primary, Secondary	2186	47.87%
Certificate, Diploma	967	21.17%
Degree or Higher	1414	30.96%
Totals	*4567*	*100.00%*
Social Class		
Professional Workers	659	16.10%
Managerial & Technical	1074	26.25%
Non Manual	314	7.67%
Skilled & Semi Skilled Manual	2045	49.98%
Totals	*4092*	*100.00%*
Ethic or Cultural Background		
Irish	3480	*79.18%*
Irish Traveller, Other White Background	522	*11.88%*
African, Other Black Background	258	*5.87%*
Chinese, Other Asian Background	135	*3.07%*
Totals	*4395*	*100.00%*

Table 16: Study Children Screened and Parental Study Booklet Returns at National Schools for Senior Infants

National Schools		Males		Females		Totals	
		n	%	n	%	N	%
Senior Infants	Screened	10	71.43%	4	28.57%	11	100.00%
	Returns	4	66.67%	2	33.33%	6	100.00%

Table 17: Study Children Screened and Parental Returns at National Schools for Special Education Units

National Schools		Males		Females		Totals	
		N	%	N	%	N	%
Special Education Units	Screened	6	75.00%	2	25.00%	8	100.00%
	Returns	6	85.71%	1	14.29%	7	100.00%

Table 18: Study Children Screened and Parental Returns at National Schools for Autism Units

National Schools		Males		Females		Totals	
		N	%	N	%	N	%
Autism Units	Screened	12	66.67%	6	33.33%	18	100.00%
	Returns	11	78.6%	3	21.40%	14	100.00%

CHAPTER 5
THE SOCIAL COMMUNICATION QUESTIONNAIRE
RESULTS FOR NATIONAL SCHOOLS

1.0 Introduction

As discussed in Chapter 3 the majority of study booklets were completed by the study child's mother. Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) descriptive statistics will be described for the whole sample and stratified for the study child's and primary care givers socio demographic characteristics. Scores will also be stratified for children with and without parent reported social, communication, or co-ordination disorders.
Stratification of the sample relating to diagnostic status for children identified with parent reported developmental disorders will be analysed in detail in the proceeding chapters. The response pattern for the (n = 39) SCQ questions on which the total score is calculated and specifically for SCQ questions developed based on the Autism Diagnostic Interview Revised (ADI-R) domains will also be explored.

As this study is the first attempt to screen a representative epidemiological sample of primary school aged children (with and without developmental difficulties) for autism spectrum disorder, there is limited comparative data available for previous studies which used the SCQ as a primary screening instrument in the general population.

The findings explored in this chapter will be compared against data from two studies.
The first study by Mulligan *et al.,* (2009) screened a small sample of primary school children (n = 240) 5-13 years of age with the objective of describing the distribution of SCQ scores in the general population to identify if traits from all domains of autism were present.
The second study by Chandler *et al.,* (2007) examined the properties of the SCQ in a population cohort of children 9-10 years of age with ASDs (n = 255) and in the general population (school sample = 411) (general population sample (n = 247). Emphasis will be placed on comparing the results of the present study with the school and general population sample findings.

2.0 Study Methodology

2.1 The Sample

There were (n = 5589) study booklets completed by parents, 2% (n = 131) of these cases were excluded from the national school dataset as a high percentage of background and SCQ questions (SCQs unanswered: range: 0 – 12) were also incomplete. Completed study booklets available for analysis (n = 5458).

2.2 Objectives

To describe to distribution of SCQ total score for the national school population of (n = 5457) study booklet returns.

2.3 Statistical Analysis

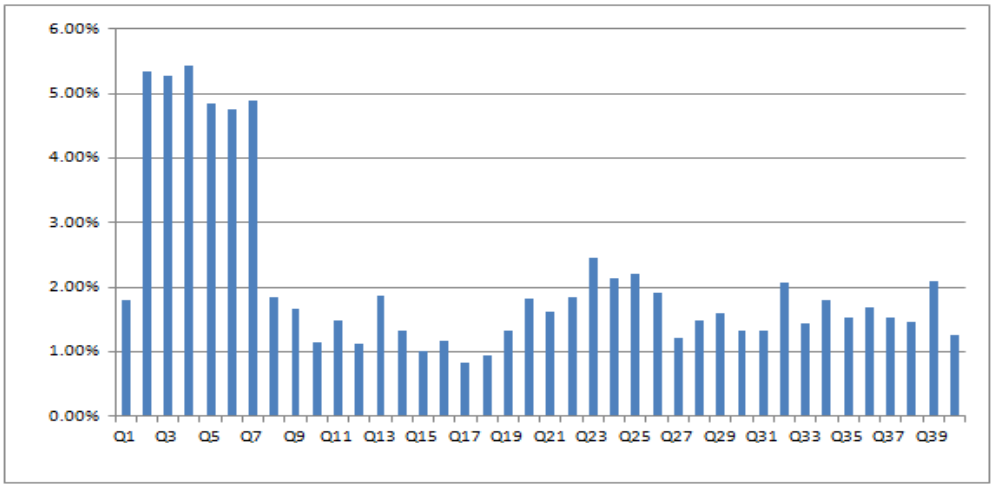
The following statistical tests will be used for the preliminary analysis of SCQ data in this chapter: Chi Square, Independent t tests, and One Way ANOVA's for the national school sample.

3.0 Results

3.1 SCQ Questions Completed by Primary Caregivers

Seventy nine percent (n = 4318) of primary caregivers answered all 39 questions. Question one is a filter question related to whether the study child was able to speak in short sentences and phrase. Four percent of parents answered no to this question (n = 216) questions 2-7 which relate to language use were not applicable. On initial assessment of the frequencies of incomplete questions there did not appear to be any questions which were not understood (not answered) in high frequencies by primary caregivers, see Figure 7.

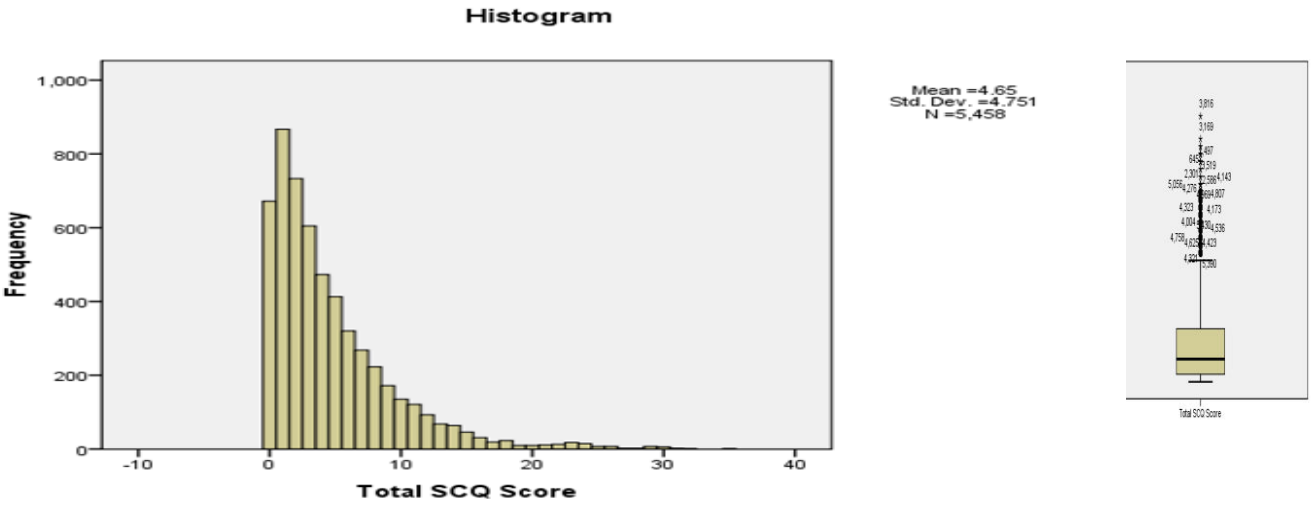
Figure 7: Percentage of Questions Unanswered by Primary Caregivers for National School Children



3.2 Distribution of Scores

The distributions of scores were strongly skewed towards lower scores, Mean = 4.65 (95% CI: 4.32-4.78) (S.E Mean = 0.064) SD = 4.75, Mode = 1, Median = 3, Skew = 1.93, Kurtosis = 5.05, range 0 - 36 for the whole sample. The majority of children scored in the normal range (0-11) 92% (n = 5002), moderate (12-14) 4% (n = 225) and high score range (≥15) (n = 230) 4%.

Figure 8: Range and Distribution of Total SCQ Scores for National School Children



3.3 Sample Characteristics & SCQ Scores

Significant differences in SCQ Total scores were not observed by age group $F(2) = 2.294$, $p > 0.05$ younger children had higher SCQ scores. Statistically significant differences in mean scores were observed by gender, which were higher for males (M = 5.07, SD = 5.04) than females (M = 4.11, SD = 4.29) $t(5380) = 7.513$, $p < 0.001$.

There were statistically significant differences by the type of school attended by study children and mean SCQ scores which were higher for children attending disadvantaged schools 6.55 (5.36) in comparison with mainstream school children 4.16 (4.49) $t(441) = -8.430$, $p < 0.001$.

There were statistically significant differences in scores observed for the study child's nationality (Irish/Non Irish) whereby Irish children's mean scores 4.56 (4.73) were significantly lower than those Non Irish children 5.26 (4.85) ($t(956.017) = -3.676$, $p < 0.001$). The lowest scores were obtained by American and Canadian 4.06 (4.49) followed by Irish children 4.56 (4.73). The highest scores were observed for Eastern European children 6.51 (4.79) $F(6, 5438) = 4.348$, $p < 0.001$, see Table 19.

In Table 19 almost twice the number of children were identified who obtained SCQ cut off scores in high score range (≥15) 6% (n = 97) enrolled at mainstream compared with disadvantaged schools 3% (n = 133) that can be explained by the significantly higher return rate at mainstream schools.

Table 19: Social Communication Questionnaire (SCQ) Scores by National School Type

	< 11		12 – 14		15 +		Totals	
School Type	N	%	N	%	n	%	n	%
Mainstream	3597	93.40%	121	3.14%	133	3.45%	3851	100.00%
Disadvantaged	1405	87.48%	104	6.48%	97	6.04%	1606	100.00%
Totals	5002	91.66%	225	4.12%	230	4.21%	5457	100.00%

Table 20: Total SCQ Scores by National School Study Children's Demographics Characteristics

Study Child's Characteristics	***SCQ Score***				
	N	***%***	***Mean***	***SD***	***95% CI***
Age (Yrs)					
6-7 yrs	2063	37.80%	4.82	4.83	4.61 ± 5.03
8-9 yrs	2013	36.88%	4.58	4.72	4.37 ± 4.78
10-11 yrs	1381	25.33%	4.5	4.65	4.25 ± 4.74
Totals	*5458*				
Gender **					
Males	3074	56.32%	5.07	5.04	4.90 ± 5.25
Females	2384	43.68%	4.11	4.29	3.94 ± 4.28
Totals	*5458*	*100.00%*			
School **					
Mainstream	3852	70.58%	4.16	4.49	4.03 ± 4.31
Disadvantaged	1606	29.42%	5.81	5.11	5.56 ± 6.06
Totals	*5458*	*100.00%*			
Nationality **					
Irish	4724	86.55%	4.56	4.73	4.42 ± 4.69
Non Irish	734	13.45%	5.26	4.85	4.91 ± 5.61
Totals	*5458*	*100.00%*			
Country of Origin**					
Irish	4724	86.55%	4.56	4.73	4.42 ± 4.69
Western European	354	6.49%	5.12	5.01	4.62 ± 5.67
Eastern European	72	1.32%	6.51	4.79	5.39 ± 7.64
Asian	130	2.38%	5.22	4.62	4.41 ± 6.04
African	79	1.45%	5.61	4.02	4.71 ± 6.51
American / Canadian	68	1.25%	4.06	4.49	2.97 ± 5.15
Other Countries	31	0.57%	5.71	6	3.51 ± 7.91
Totals	*5458*	*100.00%*			

** $p < 0.001$ * $p < 0.05$

A series of ANOVAS were also performed to explore the relationship between SCQ total score and the study child's and mothers demographic characteristics:

- Level of Education.
- Social Class.
- Ethnic or Cultural background.

Due to violations of the assumptions of homogeneity of variance further analysis could not be performed. Mean SCQ scores were higher for study children who had only obtained primary or secondary level education, working in skilled and semi-skilled manual occupations, of African or Asian background, see Table 21.

Table 21: Total SCQ Scores by National School Study Children's Mothers Demographic Characteristics

	SCQ Score				
	N	***%***	***Mean***	***SD***	***95% CI***
Study Child's Mothers Level of Education					
Primary to Secondary	2195	41.90%	5.54	4.98	5.34 ± 5.75
Diploma	1526	29.13%	4.25	4.36	4.03 ± 4.47
Degree or Higher	1518	28.97%	3.45	4.2	3.24 ± 3.66
Totals	*5239*	*100.00%*			
Study Child's Mothers Social Class					
Professional Workers	321	9.89%	2.57	3.33	2.21 ± 2.94
Managerial & Technical	1397	43.04%	4.00	4.31	3.77 ± 4.23
Non Manual	721	22.21%	3.76	3.87	3.48 ± 4.04
Skilled & Semi Skilled Manual	807	24.86%	5.44	4.63	5.12 ± 5.77
Totals	*3246*	*100.00%*			
Study Child's Mothers Ethnic, Cultural Background					
Irish	4000	80.66%	4.15	4.46	4.01 ± 4.29
Irish Traveller, Other White Background	528	10.65%	5.97	5.34	5.52 ± 6.43
African, Other Black Background	301	6.07%	6.72	5.02	6.12 ± 7.29
Chinese, Other Asian Background	130	2.62%	5.88	5.43	5.12 ± 5.77
Totals	*4959*	*100.00%*			

3.4 SCQ Scores by Diagnostic Group

Thirteen percent (n = 694) of parents reported they had concerns that the study child had social, communication or co-ordination difficulties. A One Way ANOVA was performed to explore the relationship between Total SCQ score and diagnostic status.

As a result of violations of the assumptions of homogeneity of variance (Levene Statistic = 11.194 $p < 0.001$) further exploration of this data could not be performed for the whole sample. It is important to note that the highest mean scores were observed for children waiting a diagnostic evaluation 10.39 (8.39) followed by those with a diagnosed developmental disorder 9.40 (7.94) and parents of children who reported the study child did not have a diagnosis 7.71 (6.3), see Table 22.

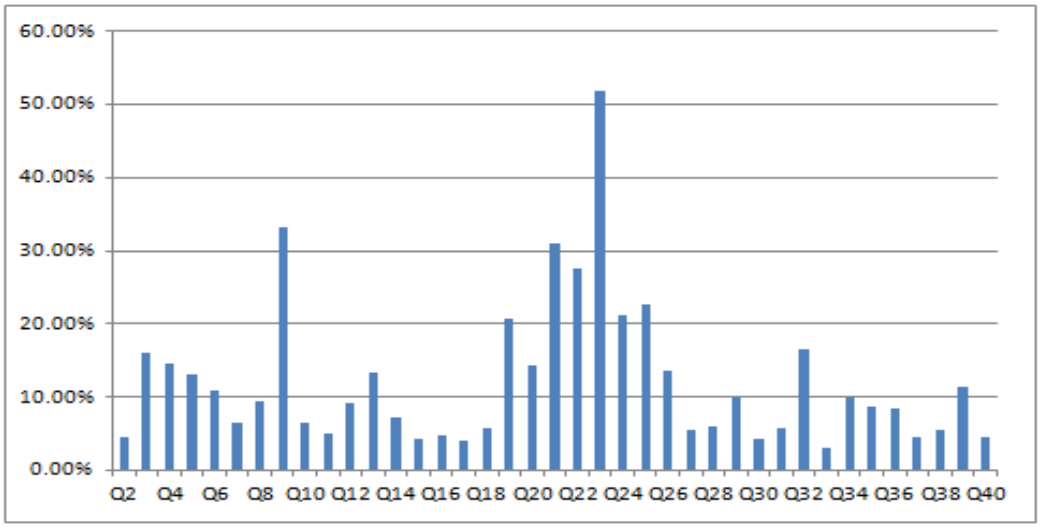
Table 22: SCQ Scores by National School Study Children's Diagnostic Status

					95% Confidence Interval for Mean			
Diagnostic Status	N	Mean	Std. Deviation	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
Yes	411	9.40	7.937	.392	8.63	10.17	0	35
No	245	7.71	6.295	.402	6.92	8.51	0	30
Pending Consultation	38	10.39	8.397	1.362	7.63	13.15	1	29
Total	694	8.86	7.467	.283	8.30	9.42	0	35

3.5 Response Pattern of SCQ Questions

The percentage of "autism-positive" responses for each of the 39 SCQ questions is presented in Figure 9. There was considerable variation in individual questions in terms of the percentage of the autism positive responses for the whole national school sample. Mulligan et al., (2009) reported a high frequency of autism positive responses to questions: Q21 (~20%) Q9 (above 15%), Q23 (above 40%) and a low frequency of autism positive responses to questions: Q33 (range of facial expression), Q17 (self injury) and Q30 (seeking to share enjoyment) (below 5%) which is similar to the findings in the current sample.

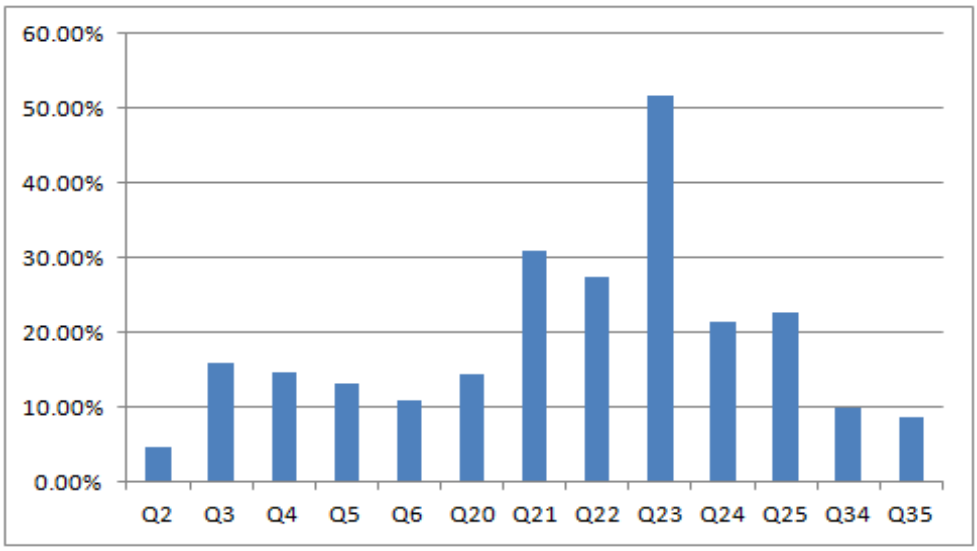
Figure 9: Percentage of Autism Positive Responses across Individual Questions of the SCQ for National School Children



The SCQ scores were explored for each of the three ADI-R domains, Communication, Reciprocal Social Interaction, and Restricted Reptititve Sterotyped Behaviour will be briefly discusssed. The pattern of autism posiitve scores in the current study are expected to be a greater representaition of school aged children in comparison to Mulligan's et al., (1999) reported findings.

In the population sample the highest frequency of autism positive responses was for Q23 (Gestures) 52% which was also reported as autism positive in by a high percentage of parnets (above 40%) in Mulligan *et al.,* (1999) school sample. The lowest percentage of autism positive responses Question 2 (Conversation) at 4% also concurs with her findings, see Figure 10.

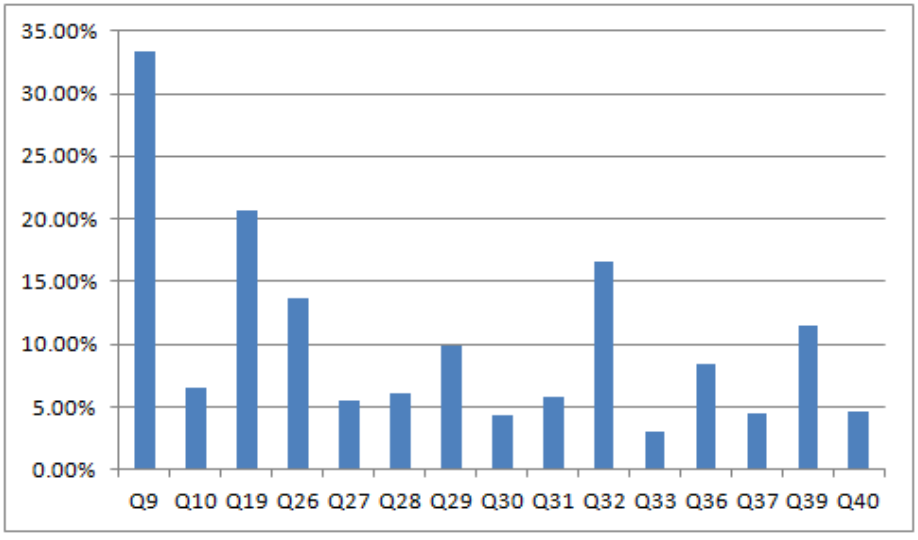
Figure 10: Response Pattern to SCQ Questions which Correspond with the Communication Domain for the ADI-R for National School Childen



Q2	Conversation
Q3	Stereotyped utterances
Q4	Inappropriate questions
Q5	Pronoun reversal
Q6	Neologisms
Q20	Social chat
Q21	Imitation
Q22	Pointing to express interest
Q23	Gestures
Q24	Nodding head to mean yes
Q25	Shaking head to mean no
Q34	Imitative social play
Q35	Imaginative play

The highest and lowest perctange of autim posiitve responses to questions based on the Reciprocal Social Interaction domain were observed for questions Q9 (Inapproerpate Facial Expressions) 33% and Q33 (Range of Facial Expressions) at 3% respectively. Mulligan et al., (1999) also reproted Q9 as the highest frequency of responses in this domain of questions (above 15%) and a low percentage of autism posiitve responses to Q33, see Figure 11.

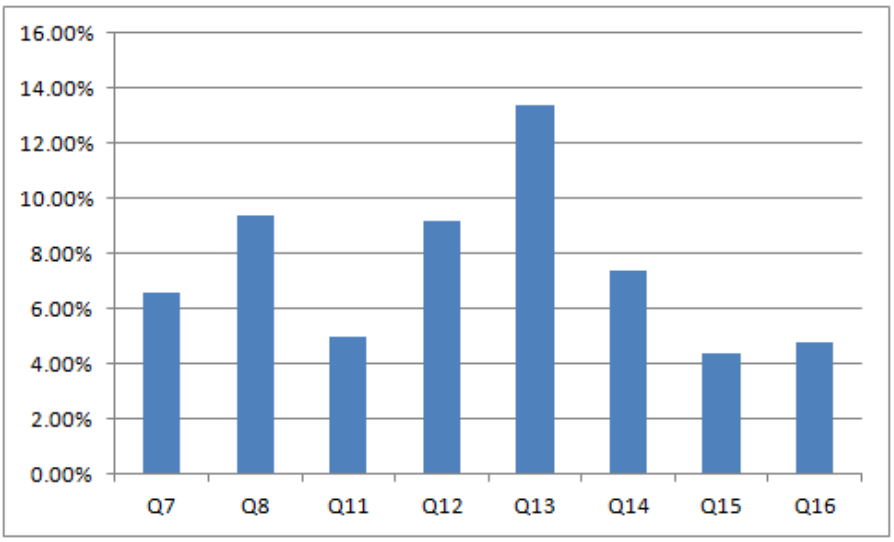
Figure 11: Response Pattern to SCQ Questions which Correspond with the Reciprocal Social Interaction Domain for the ADI-R for National School Children



Q9	Inappropriate facial expressions
Q10	Use of others body to communicate
Q19	Friends
Q26	Eye gaze
Q27	Social smiling
Q28	Showing and directing attention
Q29	Offering to share
Q30	Seeking to share enjoyment
Q31	Offering comfort
Q32	Quality of social overtures
Q33	Range of facial expressions
Q36	Interest in children
Q37	Response to other children's approaches
Q39	Imaginative play with peers
Q40	Group play

In the current study the lowest and highest perctange of autism posiitve responses to questions based on the RRSB domain were for Q15 (hand and finger mannerisms) 4% and Q13 (Circumscribed Interests) 13% respectively which agree with Mulligan's findings who also reported a high frequency of autism posiitve responses to Q8 (above 20%) which was not observed in the current study, see Figure 12.

Figure 12: Response Pattern to SCQ Questions which Correspond with the Restricted, Repetitive, and Sterotyped Patteerns of Behaviour Domain (RRSB) for the ADI-R for National School Children



Q7	Verbal rituals
Q8	Compulsions & rituals
Q11	Unusual preoccupations
Q12	Repetitive use of objects
Q13	Circumscribed interests
Q14	Unusual sensory interests
Q15	Hand & finger mannerisms
Q16	Complex body mannerisms

3.6 Discussion

The distribution of SCQ scores was similar to the findings reported by Mulligan *et al.,* (1999) and in Chandler's *et al.,* (2007) school and general population samples. Almost twice the number of children obtained cut off scores in the moderate and high scores range enrolled at disadvantaged in comparison with mainstream schools.

In the current study although there were not statistically significant differences in mean scores by age group younger children scores were higher than older age groups. Significant effects of age were also not observed in Mulligan *et al.,* (1999) study, although there appeared to be a non-significant effect of age with mean scores for 4 year old children higher than older age groups, which dropped for children in the 5-7 age groups and increased for children who were over 10 years of age.

Table 23: Children Screened with the SCQ in School & General Population Studies Reviewed

Study	Sub Sample	Age (Yrs)	N	Mean	SD	Mode	Range	Skew	SCQ ≥ 15
Irish Autism Prevalence Study	School	6 -11	5458	4.65	4.75	1.00	0 - 35	1.93	4.20%
Mulligan et al., 1999	School	5 - 13	240	3.89	2.77	1.00	0 - 20	1.59	1.80%
Chandler et al., 2007	School	9 – 10	247	4.10	4.70	-------	-------	-------	4.40%
	General Population	9 – 10	411	4.70	5.00	-------	-------	-------	5.30%

There were also statistically significant differences in mean scores by gender whereby male's scores were higher than females. Significant effects of gender were not observed in Mulligan's *et al.,* (1999) study although mean scores were higher for males. In Chander's school and general population samples a restrictive age range of children were screened 9-10 years of age, a breakdown of mean scores by gender were only provided.

To my knowledge this is the first study to reported SCQ scores by ethnic group for study children and parental social class. It was observed that mean scores were lower for children from USA / Canada followed by Irish children.

The highest mean scores were for children from Eastern Europe, African and Asia. Mothers of children who were only educated to primary or secondary level, working in skilled and semi skilled manual occupations obtained the highest mean scores. These findings indicate that literacy and language issues may explain a high percentage of these high scores specifically for children who do not have a current diagnosis of autism or other developmental disorder.

Finally there was a considerable degree of variation in the distribution of autism positive responses for each SCQ question. The response pattern of autism positive responses was similar to Mulligan *et al.,* (1999) reported findings for all SCQ questions and for those based each of the three ADI-R domains.

CHAPTER 6
THE SOCIAL COMMUNICATION QUESTIONNAIRE
RESULTS FOR SPECIAL EDUUCATION SCHOOLS

1.0 Introduction

The objective of this chapter is to describe the study population screened and returns for special education schools by age, gender, class and socio-economic characteristics for the study child, and primary caregivers. Parents who reported learning, communication, or co-ordination disorders will be described in relation to the study child's: diagnostic status, waiting times for a formal diagnosis, when primary caregivers first expressed concerns relating to the study child's difficulties in development and behaviour.

The distribution of Social Communication Scores (SCQ: Rutter *et al.,* 2003) will be described for parents who completed study booklets, cut off scores will be analysed for different diagnostic groups. Chi square testes will be used to identify SCQ questions which differentiated ASDs from other developmental disorders. Finally the sensitivity and specificity of the SCQ will be explored at the recommended cut off ($\geq$ 15) and optimal cut off scores for this sample of children.

2.0 Study Methodology

The study methodology has been described in detail in Chapter 2.

3.0 The Sample

3.1 Study Children

There were (n = 189) males 66% (n=125) females 34% (n = 64) screened across (n = 12) special education schools in Galway, Waterford and Cork, there were not significant differences by age and gender ($\chi 2$ (2) = 1.967, p > 0.05), see Table 24.

Table 24: Special Education School Study Children Screened by Age and Gender

Gender	6-7 yrs		8-9 yrs		10-11 yrs		Totals	
	N	%	N	%	N	%	N	%
Male	40	32.00%	37	29.60%	48	38.40%	125	100.00%
Female	24	37.50%	22	34.38%	18	28.13%	64	100.00%

The overall response rate was poor at 36% (n = 69) of children screened. The majority of returns were for males (n = 50) 72%, females (n = 19) 27.5%. There were not significant differences in returns by age and gender ($\chi 2$ (2) = 0.624, p > 0.05), see Table 25. The majority of study children were born in Ireland 87% (n = 60).

Table 25: Parental Participation Rates for Special Education Schools by Age and Gender

	6-7 yrs		8-9 yrs		10-11 yrs		Totals	
	N	%	N	%	N	%	N	%
Male	9	18.0%	18	36.0%	23	46.0%	50	100.0%
Female	2	10.5%	8	42.1%	9	47.4%	19	100.0%

3.2 Parent Characteristics

Ninth eight percent (n = 68) of study booklets was completed by informants who had provided most care for the study child since birth, 89% (n = 62) of study booklets were completed by biological mothers, adoptive mothers 3% (n = 2) and biological fathers 7% (n = 5). The majority of mothers were Irish born 78% (n = 46) married 68% (n = 47), homemakers 66% (n = 41), educated to primary or secondary level 46% (n = 30). Twenty six (n = 16) of working mothers were employed in non-manual 33% (n = 5) and managerial and technical occupations 26% (n = 4).

Seventy eight percent (n = 42) of fathers were Irish born, 78% (n = 44) were working (as employees or self-employed) 9% (n = 5), working in non-manual 33% (n = 14) and semi-skilled 26% (n = 11) occupations educated to primary or secondary level of education 55% (n = 31). Nine percent (n = 5) of fathers were reported as unemployed.

4.0 Results

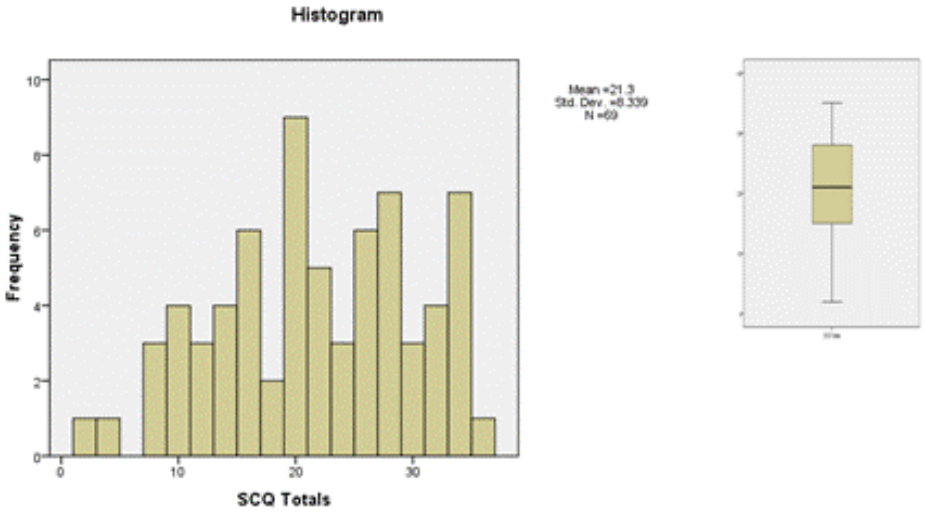
4.1 Distribution of Scores

The majority of children screened at special education schools scored at the recommended cut off ≥ 15 77% (n = 53), while 9% (n = 6) scores were in the moderate to borderline (12-14) range, descriptive statistics for the sample are provided in Table 26.

Table 26: SCQ Descriptive Statistics for Special Education Schools

Sample	N	Mean	95% (CI)	Se Mean	SD	Mode	Median	Range	Skew
Special Ed Schools	69	21.3	19.30 - 23.31	1.004	8.34	20	21	2 - 35	-0.231

Figure 13: Range and Distribution of Total SCQ Scores for National School Children



Parents reported that 99% (n = 68) of the sample had a previously diagnosed developmental disorder. There were not significant differences in total scores by gender males mean (SD) 21.64 (7.96) and females 20.42 (9.43) $t(67) = 0.540$, $p > 0.05$. Significant differences on age group were not observed 6-7 yrs 22.00 (9.8) 8-9 yrs 22.56 (7.2) and 10-11 yrs 19.14 (8.1) $F(2) = 1.121$, $p > 0.05$.

Fifty five percent (n = 38) of parents reported the study child was not able to speak in short phrases or sentences, scores for children without language were higher 22.90 (7.62) than children with language 20.00 (8.76), their differences were not statistically significant $t(67) = -1.0450$, $p > 0.05$.

We identified 52% (n = 36) children with a confirmed diagnosis on the autism spectrum (autistic disorder 17% n = 6; ASD 87% = 30). Children with a diagnosis of autistic disorder obtained the highest scores mean (SD) 28.33 (5.78) followed by those diagnosed with autism spectrum disorder (specific phenotypes not documented by clinicians) 24.74 (6.89). Seventh seven percent (n = 53) of children were identified at the recommended cut off score ($\geq$15) with a developmental disorder. Ninety three percent (n = 28) of children with an ASD diagnosis were identified at the recommended cut off score Two children (7% false negative rate) with a diagnosis of autism spectrum disorder (score range 9-11) were not identified at the recommended cut off score. All six children with a diagnosis of autistic disorder were identified at the recommended cut off score and above.

There was considerable variation in scores for other diagnostic groups see Table 27. Children diagnosed with autism and other ASDs had the highest mean scores. Children in the other diagnostic groups also obtained high mean scores e.g. cerebral palsy, speech and language, and genetic disorders i.e. Angleman syndrome, Hurler Syndrome, Cornelia de Lange Syndrome.

Table 27: Special Education Schools Diagnostic Groups & Descriptive Statistics for the Total the SCQ Score

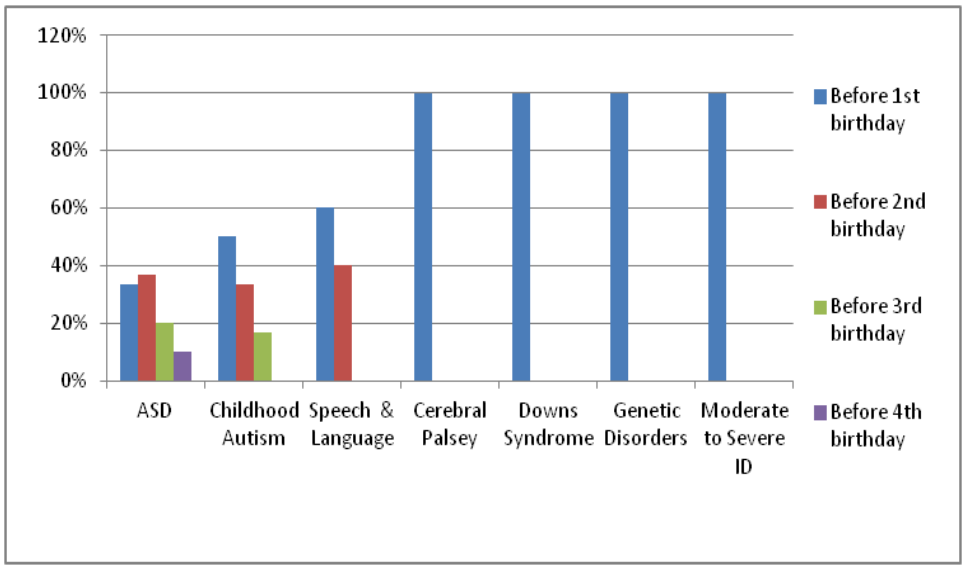
Disorders	N	%	Mean	95% CI	SD	Range	% (12-14)	% (≥ 15)
ASD	30	50.00%	24.77	22.15 ± 27.38	7.01	26 - 11	0.00%	93.50%
Childhood Autism	6	10.00%	28.33	22.26 ±34.40	5.78	19 - 34	0.00%	100.00%
Cerebral Palsy	3	5.00%	19.67	5.54 ± 33.79	5.69	15 - 26	0.00%	100.00%
Downs Syndrome	8	13.33%	15.38	8.31 ± 22.44	8.45	4 - 29	50.00%	25.00%
Genetic Disorders	5	8.33%	20.6	10.53 ± 30.67	8.11	8 - 30	0.00%	75.00%
Speech & Language	5	8.33%	21.6	10.93 ± 32.27	8.59	9 - 33	0.00%	80.00%
Moderate to Severe ID	3	5.00%	14	0.86 ± 27.14	5.29	8 – 18	0.00%	66.70%

4.2 Parent Reported Developmental Concerns

Of the children screened in the special education schools that took part in the study as expect a large number of children had developmental disabilities that were diagnosed at birth. These children were diagnosed with Cerebral palsy 2% (n = 1), Down's syndrome 10% (n = 6), moderate to severe ID 5% (n = 3). Children identified diagnosed with autism spectrum disorder composed the majority of cases disorders 58% (n = 36), Autism 17% (n = 6), autism spectrum disorder 83% (n = 30).

There were significant differences when parents expressed concerns about the study children's development and behaviour for different parental reported diagnosed developmental disorders before the child's 4th birthday ($\chi 2$ (3) = 13.758, $p < 0.00$).
The majority of parents of children diagnosed with childhood autism reported developmental concerns by 1-2nd birthday, while 83% (n = 5) of children diagnosed with ASD 70% (n = 21) expressed concerns during this period of development, see Figure 14.

Figure 14: Parent Reported Developmental Concerns for National School Children



4.3 Item Validity

Chi square tests were performed to identify questions that differentiated autism spectrum from other neurodevelopmental disorders, 56% (n=22) questions showed statistically significant differentiation, see Table 28. The results for SCQ questions that were based on the Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) 53% (n=19) will be explored to identify those questions that significantly differentiated ASDs from other developmental disorders for each of the three domains: Communication, Reciprocal Social Interaction and Restricted, Repetitive and Stereotyped Patterns of Interest Domains.
To my knowledge only two previous studies (Evan's *et al.,* 2006; Berument *et al.,* 1999) performed item analysis to differentiate ASD from not spectrum disorders. In the validation study 85% of questions differentiated ASDs from other developmental disorders. This study included both adults and children 2-40 years of age who were participants in previous studies. The parents of these children had been previously interviewed with the ADI or ADI-R which may have inflated SCQ scores.

Evans *et al.,* (2006) study included a cohort of preschool children (n = 151) who were referrals for ASD assessments 46% of SCQ questions differentiated ASDs from other developmental disorders. The findings of these studies are not comparable with the current study given that the validation study (Berument *et al.,* 1999) included both adults and children. The study by Evans *et al.,* (2006) included pre-school children.

Table 28: SCQ ADI-R Domain Questions (Endorsed / Not Endorsed) for Special Education School Children with ASDs

Social Questionnaire Questions (SCQ)	ASDS	
	Not Endorsed	Endorsed
Reciprocal Social Interaction:		
Q10. Use of others body **	27.80%	72.30%
Q26. Eye gaze *	33.30%	66.70%
Q27. Social smiling **	50.00%	50.00%
Q30. Seeking to share enjoyment **	36.10%	63.90%
Q31 Offering Comfort *	36.10%	63.90%
Q32. Quality of social overtures **	44.40%	55.60%
Q33. Range of facial expression **	27.80%	72.20%
Q36. Interest in children **	19.40%	80.60%
Q37. Response to other children *	30.60%	69.40%
Communication:		
Q2. Conversation *	44.40%	55.60%
Q21 Imitation *		
Q22. Pointing to express interest. **	22.20%	77.80%
Q23. Gestures *		
Q34. Imaginative social play **	22.20%	77.80%
Restricted, Repetitive Stereotyped Behaviour :		
Q8. Compulsions & rituals *	22.20%	77.80%
Q11. Unusual preoccupations **	27.80%	72.20%
Q12. Repetitive use of objects ***	13.90%	86.10%
Q13. Circumscribed interests *	30.60%	69.40%
Q15. Hand & finger mannerisms **	19.40%	80.60%
Q16. Complex body mannerisms *	25.00%	75.00%
Not in Algorithm -		
Q18. Attention to voice *	41.70%	58.30%
Q38. Attention to voice ***	19.40%	80.60%

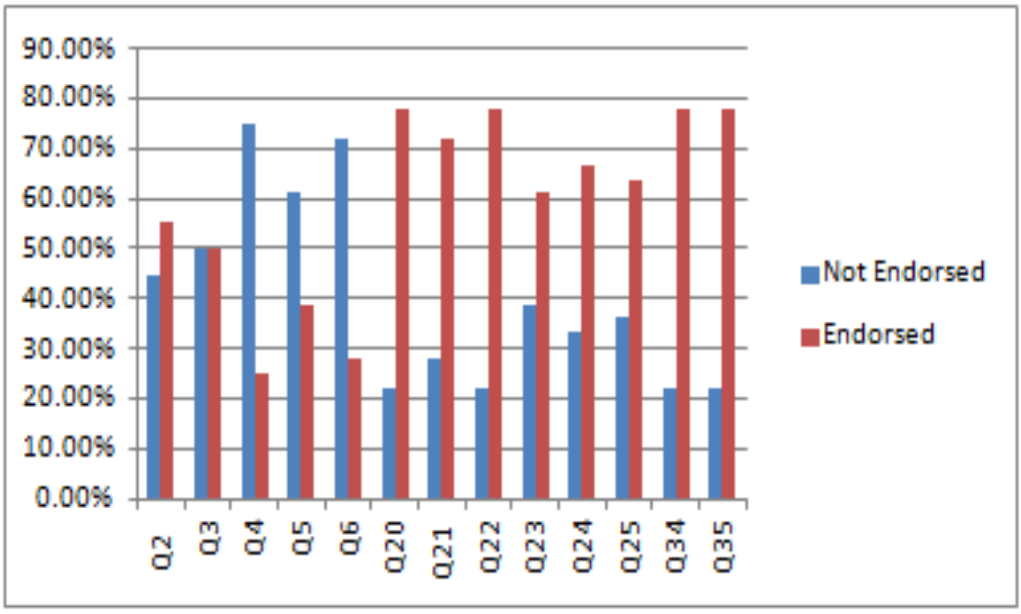
* $p < 0.05$, ** $p < 0.001$

4.3.1 Communication Domain of the ADI-R

Thirty one percent (n = 4) of SCQ questions differentiated ASDs from other developmental disorders. The following questions did not significantly differentiate ASDs from other developmental disorders: Q3 Stereotyped utterances, Q4 Inappropriate questions, Q5 Pronoun reversal, Q6 Neologisms, Q20 Social chat, Q21 Imitation, Q24 Nodding head to mean yes, Q25 shaking head to mean no.

The following SCQ questions developed based on the ADI-R Communication domain were less frequently endorsed by parents of children with a diagnosis of autism spectrum disorder: Q4 Inappropriate questions 25%, Q5 Pronoun reversal, Q6 Neologisms 29%, see Figure 15.

Figure 15: ADI-R Communication Questions (Endorsed / Not Endorsed) for National School Children with an ASDs Diagnosis



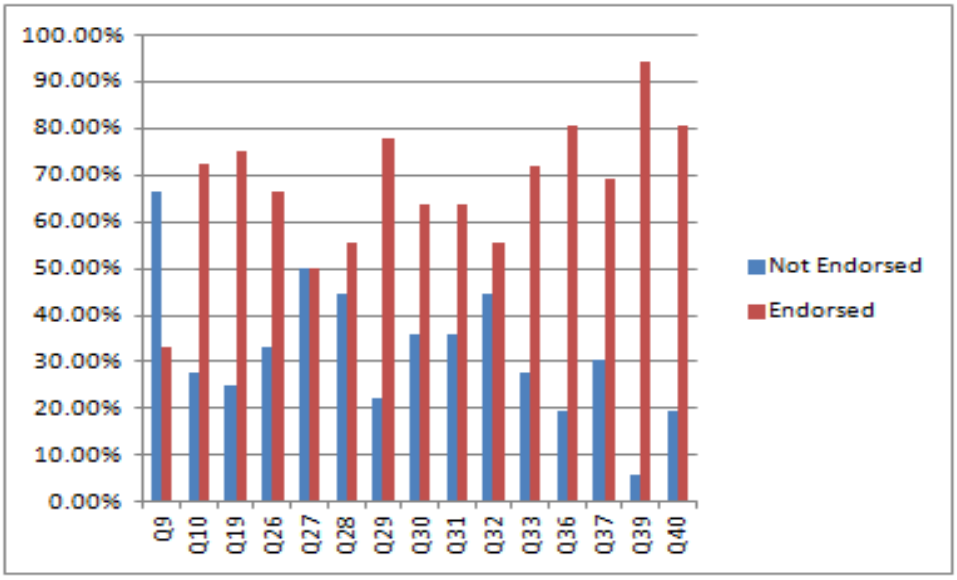
Q2	Conversation
Q3	Stereotyped utterances
Q4	Inappropriate questions
Q5	Pronoun reversal
Q6	Neologisms
Q20	Social chat
Q21	Imitation
Q22	Pointing to express interest
Q23	Gestures
Q24	Nodding head to mean yes
Q25	Shaking head to mean no
Q34	Imitative social play
Q35	Imaginative play

4.3.2 Reciprocal Social Interaction (RSI) Domain of the ADI-R

Sixty percent (n = 9) questions in the (RSI) domain differentiated ASDs from other developmental disorders. The questions which did not are as follows: Q9 Inappropriate facial expressions, Q19 Friends, Q28 Showing and directing attention, Q29 Offering to share, Q31 Offering comfort, Q40 Group play.

The following SCQ questions developed based on the ADI-R Reciprocal Social Interaction domain (RSI) were less frequently endorsed by parents of children with a diagnosis of autism spectrum disorder: Q9 Inappropriate facial expressions 33%, and Q27 Social smiling 50% see Figure 16.

Figure 16: ADI-R Reciprocal Social Interaction Questions (Endorsed / Not Endorsed) for National School Children with an ASD Diagnosis

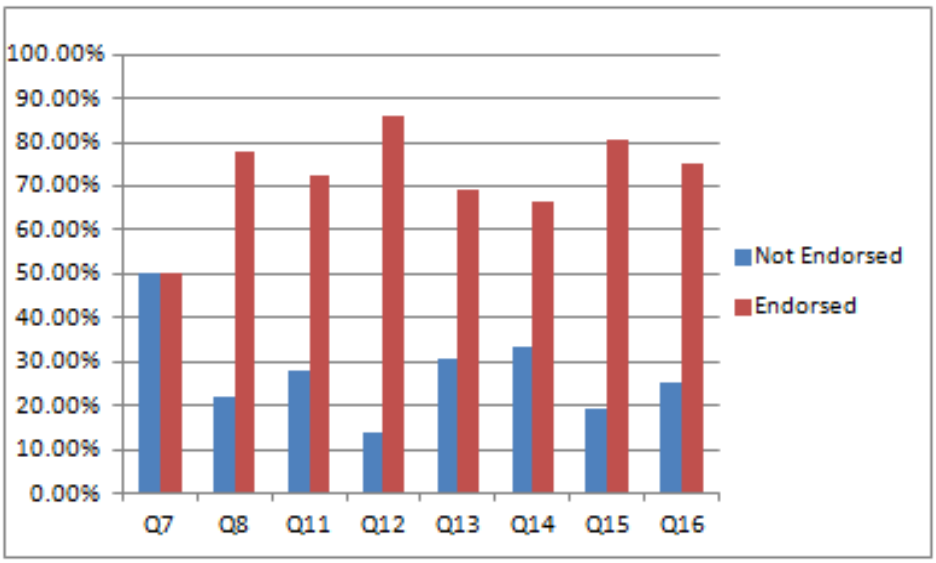


Q9	Inappropriate facial expressions
Q10	Use of others body to communicate
Q19	Friends
Q26	Eye gaze
Q27	Social smiling
Q28	Showing and directing attention
Q29	Offering to share
Q30	Seeking to share enjoyment
Q31	Offering comfort
Q32	Quality of social overtures
Q33	Range of facial expressions
Q36	Interest in children
Q37	Response to other children's approaches
Q39	Imaginative play with peers
Q40	Group play

4.3.3 Restricted Repetitive and Stereotyped Patterns of Behaviour (RRSB) Domain of the ADI-R

Eighty seven percent (n = 7) questions based on the RRSB domain significantly differentiated ASDs from other developmental disorders, only one question Q14 Unusual sensory interests did not. Only one questions developed based on the ADI-R Restricted Repetitive & Stereotyped Patterns of Behaviour domain (RRSB) was less frequently endorsed by parents of children with a diagnosis of autism spectrum disorder Q7 Verbal rituals 50%, the majority of questions were frequency endorsed by the parents of these children see Figure 17.

Figure 17: ADI-R Restricted Repetitive & Stereotyped Patterns of Behaviour (RRSB) Questions (Endorsed / Not Endorsed) for National School Children with an ASD Diagnosis



Q7	Verbal rituals
Q8	Compulsions & rituals
Q11	Unusual preoccupations
Q12	Repetitive use of objects
Q13	Circumscribed interests
Q14	Unusual sensory interests
Q15	Hand & finger mannerisms
Q16	Complex body mannerisms

5.0 Discussion

Children were screened in special education schools, as part of the Irish Autism Prevalence Study, response rates from parents to take part in the study were low 36%. One explanation for the poor response rates was that fieldworkers were unable to follow up parents of children directly through teachers at these schools who did not return completed study booklets once they were sent out by school principals. Direct engagement with teachers was an essential component of fieldwork at national schools to achieving an overall response rate 70%. Schools were requested to provide a summary of children eligible to participate in the study with a confirmed diagnosis on the autism spectrum.

There were no significant differences between the age and gender of children screened at special education schools. As expected the majority of completed study booklet returns were for males 72%. The majority of booklets were completed by mothers who were predominantly Irish born, married, homemakers, educated to primary or secondary level education. The majority of fathers were Irish born working in non-manual semi-skilled occupations, educated to primary & secondary level of education, 9% of fathers were unemployed. Parents educated to degree level and higher working in professional occupations were least represented in the sample.

Ninety nine percent of study children had a professionally diagnosed neuropsychiatric disorder. The majority of children had a diagnosis on the autism spectrum disorder 53% (autistic disorder 17%; ASDs 83% M: F ratio 29: 2). The majority of children with a diagnosis on the autism spectrum were males: ASD 93%, Autistic Disorder 83%.

The most prevalent developmental disorders at national schools included ASDs, Downs Syndrome, genetic and speech and language disorders. Among the special education school cohort 83% of children diagnosed with autism parents expressed developmental concerns before the 2nd birthday, with 70% of parents with ASD diagnosis expressing concerns during this developmental stage. Unlike the national school cohort children had neuropsychiatric disorders diagnosed since birth which included: Down's syndrome, Cerebral Palsy and genetic disorders (Angleman Syndrome, Tuberous Sclerosis, and Hurler Syndrome).

Seventy seven percent of children's SCQ total scores were above the recommended cut off point (≥15) 77% with 9% of children obtaining scores in the moderate score range. Although all children with a diagnosis of autism were identified at the recommended cut off. The majority of children with a diagnosis of ASD were also identified at the recommended cut off (there were two false negatives ASDs (score range: 9-11).

Mean scores for children with a diagnosis of autism 28.33 and other ASDs 24.74 were significantly higher than reported in previous studies which included samples of school aged children. Studies performed by Corsello *et al.,* 2007; Charman *et al.,* 2007; and Chandler et al., 2007 included samples of children referred for ASD assessments. All children in the current study had a confirmed diagnosis of autism or other neuropsychiatric disorder so it is possible that the parents of these children may have been sensitised to questions included in the SCQ (inflating their scores) through educating themselves about autism spectrum disorders. The studies performed by Charman *et al.,* (2007) and Chandler *et al.,* (2007) mean scores were higher than those reported by Berument *et al.,* (1999) and Corsello *et al.,* (2007) as older children were screened in these studies in restricted age ranges.

Item analysis was performed to identify questions that differentiated ASDs from other developmental disorders. Berument *et al.,* (1999) reported 85%; Evan's *et al.,* (2006) reported 46% of questions differentiated ASDs from other developmental disorders. In the current study 56% of all questions differentiated ASD from other developmental disorders. In comparison to the current study, the samples of children in the validation study diagnosed with childhood autism, and other phenotypes were significantly larger, and included both adults and children. As explained previously scores may have been inflated as a large number of parents had been interviewed on the ADI-R before completing the SCQ. Although all children in the current sample had diagnosed disorders few had been interviewed on the ADI-R.

Only 31% of SCQ questions developed based on the ADI-R Communication domain differentiated ASDs from other developmental disorders among the sample of special education school children screened. Questions based on the other two domains were more effective RSI domain 60% and RRSB domain 87%.

Among this cohort of children the majority of SCQ questions based on the ADI-R (RSI) and (RRSB) domains were positively endorsed by the parents of for children with a diagnosis of autism spectrum disorder apart from the questions related Q9 “Inappropriate Facial Expression” Q27 “Social Smiling” and Q7 ”Verbal Rituals”. Three questions based on the ADI-R Communication were not frequently endorsed by the parents of children with an ASD diagnosis Q4 “Inappropriate Questions” Q5 “Pronoun Reversal” Q6 “Neologisms”.

In conclusion response rates at special education schools were significantly lower than those obtained at national schools, fieldworker liaison with teachers was an essential component to obtaining the response rates. Parents educated to degree level and higher, working in professional & managerial technical occupations were underrepresented among parental participation. The majority of children in this sample had a diagnosis other than autism spectrum disorder, the majority were males. A significant number of children had developmental disorder other and ASDs which were diagnosed since birth.

The parents of other children reported they were aware of developmental difficulties by the first two years of life. The majority of children in this sample obtained scores at or above the recommended cut off score which hindered the SCQ performance of differentiating between children with ASDs from other developmental disorders. All children with a diagnosis of autism were identified at the recommended cut off score. There were two false negatives with a broad spectrum diagnosis of autism spectrum disorder identified. The majority of SCQ questions developed based on the ADI-R RSI and RRSB domains differentiated children with ASDs from other developmental disorders. SCQ questions based on the ADI-R Communication domain were less effective.

CHAPTER 7
AUTISM SPECTRUM DISORDERS
COMPARISION OF CHILDREN IDENTIFIED
AT NATIONAL & SPECIAL EDUCATION SCHOOLS

1.0 Introduction

In this chapter the characteristics of children identified with a confirmed diagnosis of autism spectrum disorder enrolled at national and special education schools will be compared (mean SCQ scores) and clinical data abstracted from psychological and multidisciplinary assessments explained to characterise the cognitive profiles, together with results from the ADOS / ADI-R where these administered as part of the diagnostic process. Difficulties encountered requesting consent to access these records, and quality of the clinical data available in these routine reports will be discussed.

2.0 Study Methodology

The study methodology has been described in detail in Chapter 2.

3.0 The Sample

Children 6-11 years of age were screened at national schools (n = 7951) and special education schools (n = 189) in three study regions, Cork, Galway and Waterford in the Republic of Ireland.

Table 29: Children Screened at National & Special Education Schools

Study Region	**National Schools**		**Special Schools**	
	n	%	n	%
Cork	1587	19.96%	82	43.39%
Galway	2773	34.88%	59	31.22%
Waterford	3591	45.16%	48	25.40%
Total	7951	100.00%	189	100.00%

4.0 Results

4.1 National Schools

At national schools a total of 58 children were identified with a diagnosis of autism spectrum disorder: males 78% (n = 45) females 22% (n = 13). Seventy six percent (n = 44) of these children were diagnosed with ASD, 24% (n = 14) with Autistic Disorder. The majority of the children in both groups were males ASD 75% (n = 33) Autistic Disorder 86% (n = 12). Mean SCQ scores were higher for children with a diagnosis of Autistic Disorder 22.14 (5.74) 95% CI: 18.83 ± 25.43 compared to children with an ASD diagnosis 21.20 (6.80) 95% CI: 19.14 ± 23.27 although differences were not statistically significant $t(56) = -0.466$, $p > 0.05$.

No statistically significant differences were observed for children diagnosed with ASD by gender: males 21.52 (6.44) females 20.21 (8.05) $t(42) = 0.520$, $p > 0.05$, nor for those diagnosed with Autistic Disorder males 22.50 (6.14) females 20.00 (1.41) $t(12) = 0.555$, $p > 0.05$.

The majority of children with a diagnosis of Autistic Disorder were identified at the recommended cut off score of 15 or over 93% (n = 13), and only one male was not so identified (Score = 10). Seventy nine percent (n = 35) of children with a diagnosis of ASD scored in the 15 or over range, 11% (n = 5) scored in the borderline range (12-14), while only 9% (n = 4) were in the normal range (score range 6-10). No statistically significant differences were observed between groups (ASD/Autistic Disorder) in the proportions below 15, and at or above 15 $\chi^2(2) = 1.865$, $p > 0.05$.

There were significant differences in SCQ scores between children with a diagnosis of ASD by age group F(2) = 4.297, p = 0.020 scores. The highest scores were observed for children in the 8-9 year age group. No significant differences were observed for children diagnosed with Autistic Disorder F(2) = 14.774, p > 0.05 see Table 30.

Table 30: Mean SCQ Total Scores for National School Children Diagnosed on the Autism Spectrum

	Autism Spectrum Disorder Score Range			Childhood Autism Score Range		
Age Group	Mean	95% CI	SD	Mean	95% CI	SD
6-7 yrs	20.55	17.67 ± 23.43	16.15	24 .00	12.86 ± 35.14	8.97
8-9 yrs	25.15	22.12 ± 28.18	5.14	21.5	17.70 ± 25.30	3.62
10- 11 yrs	17.73	12.43 ± 23.03	7.88	20.33	14.60 ± 26.07	2.31

4.2 Special Education Schools

At special education schools 83% (n = 30) of children were diagnosed with ASD and 17% (n = 6) diagnosed with Autistic Disorder 17% (n = 6). Mean scores were higher for children with a diagnosis of Autistic Disorder 28.33 (5.78) 95% CI: 22.26 ± 34.40 compared to those with an ASD diagnosis 24.77 (7.00) 95% CI: 22.15 ± 27.38, differences were not statistically significant t(34) = -1.166, p > 0.05.

The majority of children in both diagnostic groups were males ASD 93% (n = 38) and Autistic Disorder 83% (n = 5). Mean scores were higher for children in the ASD group males 24.07 (6.72) females 34.50 (0.70) t(28) = -2.158, p = 0.040. Mean scores for males in the Disorder Autistic Group were 27.40 (5.94) there was only one female in this group (Score = 33).

All children 100% (n = 6) with a diagnosis of Autistic Disorder identified at special education schools scored at or above the recommended cut off score 15+. Ninety three percent (n = 28) of children in the group ASD scored in the ≥ 15 score range, 7% (n = 2) of children obtained scores in the 12-14 score range.

There were no significant differences between children with a diagnosis of ASD/Autistic Disorder by age group scores were higher for younger children Table 31.

Table 31: Mean SCQ Total Scores for Special Education School Children Diagnosed on the Autism Spectrum

Age Group	Autism Spectrum Disorder Score Range			Childhood Autism Score Range		
	Mean	95% CI	SD	Mean	95% CI	SD
6-7 yrs	26.22	19.10 ± 33.25	9.27	27	----------	----------
8-9 yrs	24.36	21.83 ± 26.90	3.78	33.00	30.52 ± 35.48	1
10- 11 yrs	23.9	18.23 ± 29.57	7.92	22.00	-16.12± 60.12	4.24

4.3 Comparison of National & Special Education Schools

Mean scores were compared for children enrolled at national and special education schools diagnosed with ASD and Autistic Disorder. There were no significant differences in mean scores for males with an ASD diagnosis enrolled at national and special education schools. Marginally significant differences were observed for females who obtained higher scores compared to those enrolled at national schools, see Table 32.

Table 32: Mean SCQ Total Scores for Children Diagnosed on the Autism Spectrum

School Type	National			Special Ed			
	Mean	95% CI	SD	Mean	95% CI	SD	t test
Males	21.52	19.23 ± 23.80	6.44	24.07	21.47 ± 26.68	6.72	-1.514 on 59 d.f., n.s.
Females	20.27	14.86 ± 25.68	8.05	34.5	28.15 ± 40.85	0.707	2.410 on 11 d.f p = 0.035

Significant differences in mean scores were not observed for males with a diagnosis of Autistic Disorder enrolled at national and special education schools. There was only one female enrolled at special education schools with a diagnosis of autistic disorder as such comparisons are not reported, see Table 33.

Table 33: Mean SCQ Total Scores for Children Diagnosed with Autistic Disorder

School Type	National			Special Ed			
	Mean	95% CI	SD	Mean	95% CI	SD	t test
Males	22.5	18.60 ± 26.40	6.14	27.4	20.00 ± 34.78	5.94	-1.512 on 15 d.f., n.s.
Females	20.00	7.29 ± 32.71	14.14	33.00	----------	-------	

There were no significant differences were observed in SCQ scores, for children diagnosed with Autism Spectrum Disorder, by type of school attended (national vs. special education) and age group, Table 34.

Table 34: Mean SCQ Total Scores for Children Diagnosed with Autism Spectrum Disorder

Age Group	National School		Special School		
	Mean	SD	Mean	SD	**t-test**
6-7 yrs	20.55	16.15	26.22	9.27	-1.96 on 27 d.f., n.s.
8-9 yrs	25.15	5.01	24.36	3.78	0.42 on 22 d.f., n.s.
10-11 yrs	17.73	7.88	23.9	7.92	-1.79 on 19, d.f., n.s.

There was only child identified in the 6-7 age bracket with a diagnosis of Autistic Disorder enrolled at special education schools (score = 27) the child's score was higher than the mean score for males 24.00 (8.97) in this age bracket enrolled at national schools. There were only statistically significant differences in scores for children diagnosed with Autistic Disorder in the 8-9 year age bracket, scores were higher for those enrolled at special education 33.00 (1.00) compared to national schools 21.50 (3.62), see Table 35. .

Table 35: Mean SCQ Total Scores for Children Diagnosed with Autistic Disorder

Age group	National Schools		Special Schools		
	Mean	SD	Mean	SD	t-test
6-7 yrs	24	8.98	27 (one child)	---------	----------
8-9 yrs	21.5	3.62	33.00	1.00	-5.24 on 7 d.f., p=0.001
10-11 yrs	20.33	2.31	22.00	4.24	-0.59 on 3 d.f., n.s.

4.4 Confirmation of Diagnosis of ASD for Children Enrolled at National Schools

One objective of the screening protocol was to validate parent reported diagnosis for children who scored in moderate (12-14) and high score range (>15). Nineteen percent (n = 78) of all parent reported diagnosis for national school children were abstracted from psychological and multi-disciplinary assessments. Seventy four percent (n = 43) of parent reported diagnosis of autism spectrum disorder were verified from psychological and multidisciplinary assessments. Eighty eight percent records abstracted for parent reported diagnoses on the autism spectrum were correctly reported by parents in the study booklet.

The remaining 12% (n =5) of parent reported diagnosis where records were abstracted were diagnosed in 2011/12 when fieldwork was completed. Six parents reported a diagnosis of autism spectrum disorder in the study booklet, on following up the parents of these children to verify access to psychological assessments and confirm if the clinicians details provided were correct the parents reported that these children did not have a diagnosis of any developmental disorder. Some of these children obtained high scores who will be followed up to determine if they require ADOS / ADI-R assessments. Sixty two percent of other developmental disorders where records abstracted were correctly reported in the study booklet. The diagnosis confirmed from assessments for the remaining 37% were not autism spectrum disorders.

Table 36: Confirmation of Parent Reported Diagnosis for National School Children

Outcome of Record Abstraction	ASDs		Other Diagnosis		Undiagnosed	
	N	%	N	%	N	%
1. Abstraction of Psychological Assessments						
Confirmed Diagnosis						
Agrees with Parental Report	38	65.52%	22	6.23%		
Parent Report did not Correspond to Clinical Diagnosis	5	8.62%	13	3.68%		
2. Parental Follow up						
Parent Reported ASD confirmed as Undiagnosed					6	85.71%
Parent Reported ASD Confirmed as on Waiting List					1	14.29%
3. Unconfirmed Diagnosis	15	25.86%	318	90.08%		
Totals	**58**	**100.00%**	**353**	**100.00%**	**7**	**100.00%**
Grand Total	411					

Just under 1% of children screened (n = 58) were identified with a diagnosis on the autism spectrum, excluding invalid cases, autism spectrum disorder 76% (n = 44) and Autistic Disorder / Childhood Autism 24% (n = 14) at national schools.

All parent reported diagnosis of Autistic Disorder / Childhood Autism (n = 14) 100% were confirmed as correctly reported on abstraction of psychological and multidisciplinary assessments. Ninety percent (n = 26) of parent reported cases of ASD were correctly confirmed by parents from the child's assessments.

The remaining (n = 3) 10% cases of ASD were not diagnosed until after fieldwork was completed. The parents of these children had reported a diagnosis of mild learning difficulties, dyspraxia and ADHD, two of these children had only been diagnosed in September 2011, the remaining diagnosed as recently as February 2012.

4.5 Abstraction of Psychological and Multidisciplinary Assessments for Children Enrolled at National Schools

Autism Spectrum Disorder assessments teams were contacted with written parental consent to request access to psychological assessments for parents of study children who recorded in the study booklet the child had been diagnosed with autism spectrum disorder.
The majority of diagnoses on the autism spectrum (43/58) 74% were performed through multidisciplinary assessments, carried out between 2002 and 2007, which included cognitive tests, home and school observation, parent and teacher interviews, adaptive functioning assessments and social worker intervention. These children ranged in age from 2–11 years of age when they were diagnosed.

Cognitive assessments were done on 46% (n = 20) of confirmed cases, and included the Griffiths Developmental Scale, the British Ability Scales, and the Wechsler Pre School and Primary Scale of Intelligence. Language assessments were performed using the Clinical Evaluation of Language Fundamentals, and Adaptive Functioning Assessments with the Vineland Adaptive Behavioural Scales.

The Autism Diagnostic Observation Schedule (ADOS: Lord *et al.,* 2000) 35% (n = 15) was only done as part of the assessment process from 2005 onwards. The Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) was done for 21% (n = 4) confirmed cases. The Diagnostic Interview for Social & Communication Disorders (DISCO Wing, Leekam, Libby, Gould, Larcombe, 2002) was used in place of the ADI-R for 16% (n = 7) of assessments.

Clinical data abstracted from those assessments where either the ADOS or the ADI-R and cognitive assessments were part of the diagnostic evaluation are provided in Table 37. This data only represents 45% (n = 20) of children with an ASD diagnosis and 50% (n = 7) of children with a diagnosis of Autistic Disorder or Childhood Autism.

The majority of children with an broad phenotype ASD diagnosis had average to high average fill IQ (FIQ) profiles 50% (n = 9). As a result of discrepancies between verbal IQ (VIQ) and performance (PIQ) 30% (n = 6) this data was not reported by clinicians for these children. Among 20% (n = 4) of children VIQ > PIQ, 25% (n = 5) PIQ > VIQ.

Most of these children obtained cut off on the ADOS (Modules II III) for autism (n = 8) 53%, and/or met cut offs on the ADI-R for autism spectrum disorder 20% (n = 4). However, as most of these children's IQ profiles were in the average to high average range they were assigned a broad diagnosis of ASD.

There was limited clinical data abstracted for children enrolled at national schools with a diagnosis of Childhood Autism or Autistic Disorder. The cognitive profiles of these children were available for 50% (n = 7) of the children, an 85% of these children had FIQ profiles in the low average to average range. The ADOS had only been performed for two children, both of whom met cut offs for autism. The ADI-R was not been used for any of these evaluations.

Table 37: Abstraction of Psychological & Multidisciplinary Assessments for Children Enrolled at National Schools Diagnosed with Autism Spectrum Disorder

National School Clinical Findings	ASD (N = 20)		Autistic Disorder (N = 7)	
	N	%	N	%
Met ADOS Criteria for ASD:				
ASD	4	26.67%	0	0.00%
Autism	8	53.33%	2	100.00%
Did Not Meet Cut Off Criteria	3	20.00%	0	0.00%
Totals	***15***	***100.00%***	***2***	***100.00%***
Met ADI-R Cut Off for ASD:				
Yes	4	100.00%	0	0.00%
No	0	0.00%	0	0.00%
Totals	***4***	***100.00%***	***0***	***100.00%***
FIQ IQ Profile :				
Superior	1	5.00%	0	0.00%
High Average	4	20.00%	0	0.00%
Average	6	30.00%	4	57.14%
Low Average	2	10.00%	2	28.57%
Borderline	1	5.00%	0	0.00%
Not Reported	6	30.00%	1	14.29%
Totals	***20***	***100.00%***	***7***	***100.00%***
VIQ = PIQ	8	40.00%	4	57.14%
VIQ > PIQ	4	20.00%	0	0.00%
PIQ > VIQ	5	25.00%	2	28.57%
Only FIQ Reported	3	15.00%	1	14.29%
Totals	**20**	**100.00%**	**7**	**100.00%**

4.6 Confirmation of Diagnosis of ASD for Children Enrolled at Special Education Schools

Fifty one percent (n = 35) of all parent reported diagnosis for children enrolled at special education schools were validated against psychological and multi-disciplinary assessments, which included 75% (n = 27) of parent reported diagnosis of autism spectrum disorder. All parent reported diagnosis on the autism spectrum were confirmed as correct. Twenty four percent (n = 8) of other parent reported disorders were correctly reported having abstracted children's assessments, see Table 38.

Table 38: Confirmation of Parent Reported Diagnosis for Special Education School Children

Outcome of Record Abstraction	ASDs		Other Diagnosis	
	N	%	n	%
1. Abstraction of Psychological Assessments Confirmed Diagnosis Agrees with Parental Report	27	75.00%	8	24.24%
Parental Reported did not Correspond to Clinical Diagnosis				
2. Parental Follow up Parent Reported ASD confirmed as Undiagnosed				
Parent Reported ASD Confirmed as on Waiting List				
3. Unconfirmed Diagnosis	9	25.00%	25	75.76%
Totals	**36**	**100.00%**	**33**	**100.00%**
Grand Total	69			

4.7 Abstraction of Psychological and Multidisciplinary Assessments for Children Enrolled at Special Education Schools

There was limited clinical data available for these children. Cognitive assessments 21% (n= 5) of multidisciplinary assessment included use of the Griffiths Developmental Scale, Leiter-R, British Ability Scales, and Wechsler Pre School and Primary Scale of Intelligence. These children scored in the low average to borderline IQ range. The ADOS was performed for 21% (n= 5) of these assessments using modules I and II, and all of these children obtained cut off scores for autism. The ADI-R was not part of the assessment process for any of the assessments abstracted, the DISCO was performed for (n = 6) 25% of evaluations.

5.0 Discussion

The majority of children identified at national and special education schools with a diagnosis of autism spectrum disorder were male. Children identified at national schools mean scores were higher for those with a diagnosis of Autistic Disorder compared to those identified with a broader autism spectrum diagnosis. Ninety three percent of children in the Autistic Disorder group obtained SCQ scores at the recommended cut off ($\geq$ 15) with 79% in the ASD group obtaining scores in this range. There were no significant differences in mean scores observed by gender for children in the ASD and Autistic Disorder groups, although scores were higher for males. Mean scores were higher for children in the ASD group 8-9 years of age, scores decreased with age for children in the Autistic Disorder group which were statistically significant.

All children in the Autistic Disorder group scored at the recommended cut off score with 93% in the ASD group scoring in this range. There were marginally significant differences in mean scores for children in the ASD group whereby male scores were higher, there was only one female in the Autistic Disorder group. There were no statistically significant differences by age for children with a diagnosis of ASD or Autistic Disorder scores were higher for younger children.

Mean scores for children with a diagnosis on the autism spectrum enrolled at national and special education schools were compared by age and gender. Mean scores were marginally significantly higher for females with a diagnosis of ASD, whereby scores were higher for girls enrolled in special schools.

There were no statistically significant differences for males enrolled at mainstream and special education schools with a diagnosis of autism. There were an insufficient number of females with a diagnosis of autism for comparison purposes. Significant differences in age were only observed for children 8-9 year of age with a diagnosis of autism whereby scores were higher for children enrolled at special education schools.

Nineteen percent of all parent reported diagnosis in the moderate score range were verified against psychological and multi-disciplinary assessments. Records were abstracted for 74% of parent reported diagnosis of autism spectrum disorder. Eighty-eight of percent abstracted records for parent reported diagnoses were correctly reported in study booklets.

The remaining 12% of records abstracted for parent reported diagnosis of ASD were only formally diagnosed in 2011/12 when fieldwork was completed. Six cases of autism spectrum disorder reported in study booklets were reported by parents at follow up as incorrectly reported whereby the child did not have a diagnosis of any developmental disorder. Sixty two percent of records abstracted for other developmental disorders were correctly reported in study booklet.

Fifty one percent of all parent reported diagnosis for children enrolled at special education schools were validated against psychological and multi-disciplinary assessments, which included 75% of parent reported diagnosis of autism spectrum disorder, and 24% of other developmental disorders were all correctly reported on accessing these children's records.

Validation of parent reported diagnosis was a time consuming endeavour that provided limited useful data for characterising the functioning of children with a diagnosis on the autism spectrum. Having said this, there were two objectives to accessing children's assessments:

1st objective - validate all diagnoses for all children scoring in the moderate and high SCQ score range.

2nd objective – abstract clinical data: cognitive, speech and language, adaptive behaviour and results of gold standard instruments ADOS / ADI-R for children with a confirmed diagnosis on the autism spectrum.

Clinicians were initially contacted in July 2012 requesting consent to access psychological assessments, and clinical data was abstracted from September to November 2012. Correspondence was made on a number of occasions formally by letter, followed up with telephone calls to access records for the relevant children. The outcome of the process varied considerably by service and study region:

The following problems were encountered with some services requesting access to psychological and multidisciplinary assessments:

- As discussed some services refused to provide access to children's psychological or multidisciplinary assessments even though written consent had been provided, by the parents, to the service providers.

- Other services did not provide direct access to children's records but agreed to provide the relevant clinical data on request. These services drew up their own consent forms; a number of parents who had not initially expressed concerns, did not return these consent forms to these services. Even with the consent forms returned to the service, only a fraction of the clinical data requested was provided.

Assessments performed as part of the diagnostic process varied by service type for evaluating children for autism spectrum disorder:

- The ADOS & ADI-R were rarely included as part of the multidisciplinary assessment process. In some of the multidisciplinary assessments abstracted, the results of these evaluations, (summary scores) were not reported, as the actual instruments were meant to be on the child file, but for some children they were missing.

- Cognitive, speech and language, and adaptive functioning assessments were not performed for all children.

- Children's files were not available at some services either because the child was no longer attending the services were they were initially diagnosed, or the records of interest (the child's multi-disciplinary assessment) could not be obtained from their current services for some children.

There was limited clinical data abstracted from psychological assessments for children with a diagnosis on the autism spectrum to give an accurate reflection of their overall cognitive functioning. With respect to children with a diagnosis of autism spectrum disorder where cognitive data was available for these children enrolled at national schools profiles were in the average to high average range. The ADOS was only performed for 34% of these assessments whereby 53% met cut offs for autism, 27% ASD and 20% did not met cut offs for a diagnosis on the autism spectrum. The ADI-R was only undertaken for 9% of children with an ASD diagnosis all of whom met cut off scores for a diagnosis on the spectrum.

There was insufficient clinical data abstracted for children with a diagnosis of autism and all children enrolled at national and special education schools.

In conclusion, the majority of children with a diagnosis of autism spectrum disorder obtained SCQ scores at or above the recommended cut off (≥15). Most children were of male gender, mean scores were generally high for children enrolled at special education schools. The majority of parent reported diagnosis of autism spectrum disorder verified as correct from psychological and multidisciplinary assessments. Five percent of parents with children diagnosed on the autism spectrum enrolled at national schools reported a different diagnosis in the study booklet. Six parent reported diagnosis of autism spectrum disorder were confirmed as incorrectly on follow up. The format of evaluations varied considerably by service and study region, the most comprehensive assessments were available for children who were most recently diagnosed, especially in terms of including the ADOS, ADI-R or DISCO as part for the evaluation process.

CHAPTER 8
THE SOCIAL COMMUNICATION QUESTIONNAIRE DISCRIMINANT VALIDITY FOR NATIONAL SCHOOL CHILDREN

1.0 Introduction

The SCQ (Rutter *et al.,* 2003) is a widely used screening tool for autism spectrum disorders (ASD) amongst children referred for assessment. There are several studies of the SCQ in such populations (e.g. Berument *et al.,* 1999; Charman *et al.,* 2007; Chandler *et al.,* 2007) some of which have had control groups of putatively normally developing children. There seem to be very few studies of the SCQ applied to a large general population. Mulligan *et al.,* (2009) applied the SCQ to pupils attending one primary school in Ireland. This chapter reports the psychometric properties of the SCQ in a large primary school population sample.

In the Literature Review (Chapter 1 – Section 6.0) Review of Screening Instruments for School Aged Children' studies were reviewed that had used the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as a screening instrument among samples of high risk school aged children referred for autism spectrum disorder evaluation.
A validation study of the SCQ was undertaken by Berument *et al.,* (1999) with a sample of 200 children diagnosed with a range of conditions, including autism spectrum disorder (74%, n = 148), and other developmental disorders, Rett's syndrome, conduct disorders, mental retardation, and other clinical diagnoses.

These children had participated in previous studies, their parents had been interviewed on the ADI-R, and the children were diagnosed with ASDs, and other developmental disorders, before participating on the validation study. Charman *et al.,* (2007) explored the psychometric properties of the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) Social Responsiveness Scale (SRS: Constantino & Gruber, 2005) and Childhood Behaviour Checklist (CCC: Bishop, 1998) among a sample of 119 children 9-13 years of age, with and without autism spectrum disorders, who were participants in the SNAP Cohort study.

Chandler *et al.,* (2007) also examined the psychometric properties of the SCQ among children 9-10 years of age who were participants in the SNAP cohort study with special education needs with and without ASDs, and two similar but separate age groups of children from the general population sample (n = 411) and school sample (n = 247). Diagnostic assessments were completed on a stratified sub sample of (n = 255) of the special education needs group.

Corsello *et al.,* (2007) evaluated the diagnostic discrimination of the SCQ alone, and in combination with the ADOS, among clinical and research referred samples of children 2-16 years of age (n = 590), who were consecutive referrals to two university based clinics specialising in the assessment for children with possible autism spectrum disorders.
There have been rather more studies undertaken among preschool age children to access the utility of the SCQ. Only the most comprehensive studies will be mentioned.
Evans *et al.,* (2006a) examined the utility of the SCQ among a sample of 151 children with a mean age of 5.

The screen was completed before assessments in tertiary referral autism and preschool clinics. *Evans et al.,* (2006b) compared the utility of the SCQ and M-CHAT among children aged 4-6 years of age. The M-CHAT was completed by (n = 84) parents of 2-3 year olds and SCQ by parents of (n = 94) parents of 4-8 year old children. *Snow et al., (*2008) assessed the utility of these instruments among a sample of children (n = 82) 1½ -4 years of age referred for possible pervasive developmental disorders. Allen *et al.,* (2007) estimated the sensitivity and specificity of the SCQ among (n = 81) children 2-6 years of age. Finally Lee *et al.,* (2007) screened (n = 268) children 3-5 years of age receiving preschool special education services.

The current study is the first to use the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) as a primary screening instrument in a large population based study of children enrolled at national and special education schools in three study regions in the Republic of Ireland. This chapter reports on children attending mainstream primary schools only. Results for children attending special schools are presented separately.

2.0 Study Methodology

The study methodology has been described in detail in Chapter 2. An essential component of the study relevant to data analysis in this chapter was the verification of parent reported diagnoses with parental consent. Diagnoses were validated from the records of psychological and multidisciplinary assessments for children who obtained SCQ scores in the moderate to high score range, and for all parent reported diagnosis of autism spectrum disorder.

Clinical data was abstracted from assessments for children with a diagnosis of autism spectrum disorder which included summary scores for: cognitive, language, adaptive functioning assessments. The results of ADOS and ADI-R assessments where available were also abstracted.

Prior to examining the performance of the SCQ for differentiating ASDs from other developmental disorders the composition of the national school sample with diagnosed disorders will be described. The majority of clinicians used DSM-IV-R diagnostic criteria reported the child's diagnosis as: Autistic Disorder, Asperger Syndrome, or simply recorded that the child's presentation met DSM-IV diagnostic criteria for an ASD.

3.0 Statistical Analysis

The primary objective analyses reported in this chapter is to evaluate the discriminative validity of the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) for ASDs from other developmental disorders.

- The first analysis will involve exploring the discriminative ability of the SCQ Total Score to differentiate between diagnoses for children with autism spectrum disorders from all other children with or without developmental disorders.

- The second analysis will explore the discriminative validity of the SCQ Total Score to differentiate ASDs from other diagnosed developmental disorders. Children with both high and low scores will be included in the analysis, but those without a parent reported diagnosed learning disorder will be excluded.

To assess the discriminate validity of the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) a series of receiver operating curves (Hanley & McNeil, 1982; Fombonne, 1991) were computed using MedRoC™ software, using bivariate normal models. The area under the curve (AUC) serves as an index of diagnostic accuracy (Berument *et al.,* 1999). Independent t tests were performed (see Chapter 5- computed for Special Ed Schools) to identify SCQ items that differentiated autism spectrum from other developmental disorders. The ROC analyses was repeated using the recomputed SCQ score that did not include items that failed to differentiate between the groups at the 5% level of statistical significance to explore improvements in sensitivity and specificity.

4.0 The Sample

The demographic characteristics of children enrolled at national schools were previously described in Chapter 3. The distribution of SCQ Total scores for these children was explored in Chapter 4. Seven percent (n = 411) of children were identified with diagnosed developmental disorders, 1% had a confirmed diagnosis of Autism Spectrum Disorder and 6% of other developmental disorders. The most frequently reported disorders were speech and language disorders, ADHD, ASD and Dyspraxia. The composition of disorders will be discussed in this chapter. In the analysis there are 58 children with a diagnosis of an ASD, and 353 children with other developmental disorders.

The majority of parent reported diagnoses of ASD were confirmed through abstraction of psychological assessments (n = 43) 74%, a breakdown of responses from the parents of these children is provided in Table 39. The validity of parent reported diagnosis for ASDs and other developmental disorders has been discussed in Chapter 6.

Table 39: Requesting Access to Psychological Assessments for National School Children with a Parent Reported Diagnosis on the Autism Spectrum

Outcome of Contacting Parents	National Schools	
	N	%
Parent confirmed access to psychological assessments	43	74.14%
Refused access to records by parents	7	12.07%
Refused access to records by clinicians	6	10.34%
Unable to contact parents	2	3.45%
Totals	58	100.00%

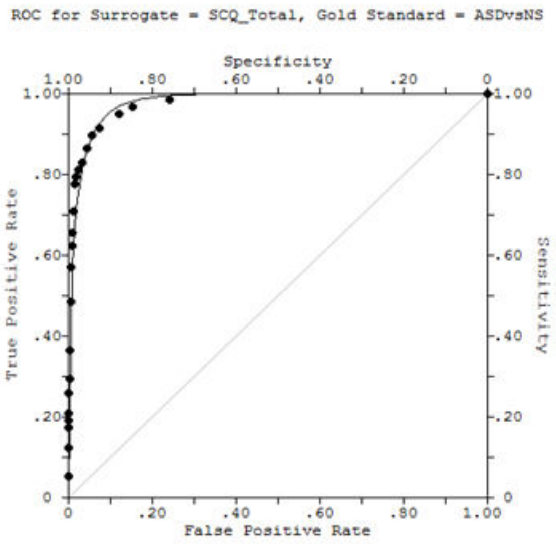
5.0 ROC Curves for the Whole National School Sample

The large majority of children (92%, n = 5002), obtained SCQ total scores in the normal range. Smaller numbers scored in the moderate (12-14) (n = 225, 4%) and high (15+) (230 = 4%) ranges. The SCQ performed well at differentiating ASDs from other diagnoses with an area under the curve (AUC) of 0.776. At the recommended cut off (15+), the sensitivity (Se) was 0.81, and the Specificity (Sp) was 0.96, for the total population of children screened. The optimal cut off score for maximising sensitivity and specificity was 12 or over see Table 40.

Table 40: Discriminant Validity of the SCQ for the Whole National School Sample Differentiating ASDs from Children With and Without Diagnosed Disorders

Optimal Cut Off	Sensitivity	Specificity	PPV	95% CI	PPV Odds Ratio	NPV	95% CI	NPV Odds Ratio
≥ = 12	0.9137	0.9255	0.1165	0.0901 ± 0.1492	12.27	0.99	0.9976 ± 0.9995	0.093

Other Cut Offs	Sensitivity	Specificity
> = 13	0.8945	0.9422
> = 14	0.8609	0.9545
> = 15	0.8142	0.9659
> = 20	0.6044	0.9882
> = 22	0.5377	0.9914



The ability of the SCQ to differentiate between ASDs and other diagnoses, or no diagnosis, was marginally better for males than for females at optimal cut off points.

Table 41: Discriminative Validity at Optimal Cut Off Points for National School Children by Gender

Gender	Mean	SD	AUC	Optimal Cut off	Sensitivity	Specificity
Males	5.08	5.03	0.9798	12 +	0.9483	0.9139
Females	4.1	4.29	0.9777	13 +	0.8685	0.9554

There were significant differences in scores by gender $t(5455) = p < 0.001$, but not by age group $F(2) = 51.590$, $p > 0.05$. Ninety seven (n = 397) of parents reported the study child had language (use of words or phrases) mean scores were higher for children who did not have language 10.90 (10.2) compared with these who did 9.38 (7.9), although differences in mean scores were not statistically significant $t(405) = -0.595$, $p > 0.05$.

Table 42: Discriminative Validity at Optimal Cut Off Points for National School Children by Age Group

Age Group	Mean	SD	AUC	Optimal Cut off	Sensitivity	Specificity
6 -7 yrs	4.82	4.83	0.9774	13 +	0.8915	0.9416
8 - 9 yrs	4.58	4.77	0.9933	16 +	0.9482	0.9749
10 - 11 yrs	4.50	4.65	0.9535	9 +	0.9183	0.8509

6.0 Children Identified with Diagnosed Disorders

6.1 The Sample

The parents of 5,457 children returned completed study booklets. A total of 411 children were reported to have a developmental or neurological problem. The majority of these children were male (293, or 71%) see Table 43.

Table 43: Diagnosed Developmental Disorders for National School Children by Gender

Neurological Diagnosis	Male		Female		Totals	
	n	%	N	%	n	%
Autistic Disorder	12	85.70%	2	14.30%	14	100%
ASD	33	75.00%	11	25.00%	44	100%
ADHD	54	84.40%	10	15.60%	64	100%
Dyspraxia	35	71.40%	14	28.60%	49	100%
S & L	150	66.10%	77	33.90%	227	100%
Down's Syndrome	7	87.50%	1	12.50%	8	100%
Other Diagnosis	2	40.00%	3	60.00%	5	100%

There were no significant differences in the diagnostic groups by age category $\chi 2$ (12) = 7.788, $p > 0.05$), see Table 44.

Table 44: Diagnosed Developmental Disorders for National School Children by Age Group

Diagnostic Group	6-7 yrs		8-9 yrs		10-11 yrs		Totals	
	n	%	N	%	n	%	N	%
Autistic Disorder	5	35.71%	6	42.86%	3	21.43%	14	100.00%
ASD	20	45.45%	13	29.55%	11	25.00%	44	100.00%
ADHD	18	28.13%	25	39.06%	21	32.81%	64	100.00%
Dyspraxia	18	36.73%	14	28.57%	17	34.69%	49	100.00%
S & L	74	32.60%	87	38.33%	66	29.07%	227	100.00%
Down's Syndrome	4	50.00%	3	37.50%	1	12.50%	8	100.00%
Other Diagnosis	2	40.00%	1	20.00%	2	40.00%	5	100.00%

6.2 SCQ Scores for Children with Parent Reported Diagnoses

Descriptive statistics for children identified with parent reported diagnoses are presented in Table 45. Children with a diagnosis of Autistic Disorder (mean/sd) 22.14 (5.73) obtained the highest scores, followed by those with ASD 21.33 (7.33) and those with AS/HFA 21.05 (6.28).

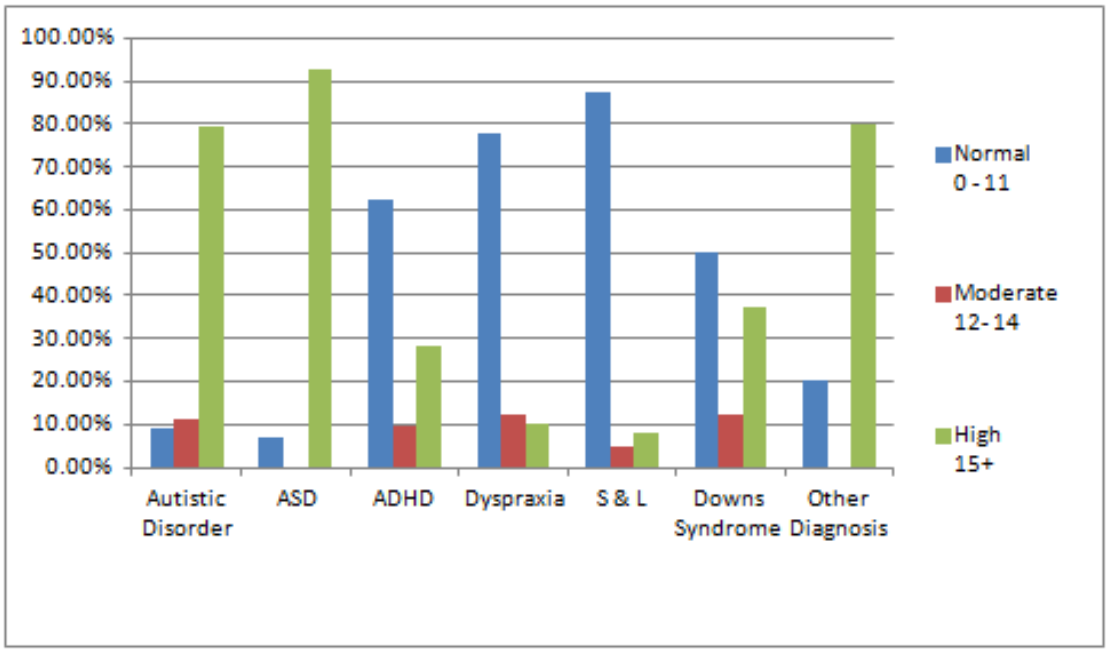
There were statistically significant differences between mean scores for all diagnosed cases of ASD 21.43 (6.52) from other combined diagnostic groups 7.42 (6.22) combined $t(409) = 15.782$, $p < 0.001$.

Table 45: Descriptive Statistics for National School Diagnostic Groups

Diagnosis	N	%	Mean	SD	95% CI	Range
Autistic Disorder	14	3.45%	22.14	5.73	18.83 ± 25.45	10 – 35
ASD	44	10.84%	21.2	6.8	19.14 ± 23.27	6 - 32
ADHD	64	15.76%	10.33	7.22	8.52 ± 12.13	0 – 31
Dyspraxia	49	12.07%	7.8	6.1	6.05 ± 9.54	0 – 30
S&L	227	55.91%	6.15	5.28	5.46 ± 6.84	0 – 29
Down's Syndrome	8	1.97%	12.63	8.31	5.66 ± 19.59	0 – 22
Other Diagnosis	5	1.23%	16	8.57	5.35 ± 26.65	2 - 25

The majority of children with a diagnosis of autism spectrum disorder were identified at or above the recommended cut off scores of 15+ (83%, n = 48). Only 8.6% of diagnosed cases of ASD were false negatives on this basis with moderate (12-14) or normal scores (0-11). Fifty percent of cases at or above the recommended cut off score (15+), were children with an ASD diagnosis followed by those with ADHD 19%, speech and language difficulties 19%, dyspraxia 5%, Down's Syndrome 3%, and other diagnoses 4%, see Figure 18. (Children in the other diagnosis category had diagnoses of emotional behavioural difficulties with and without epilepsy and obsessive compulsive disorder.

Figure 18: SCQ Cut Off Scores by Diagnostic Groups for National School Children



6.3 Receiver Operating Curves (ROC)

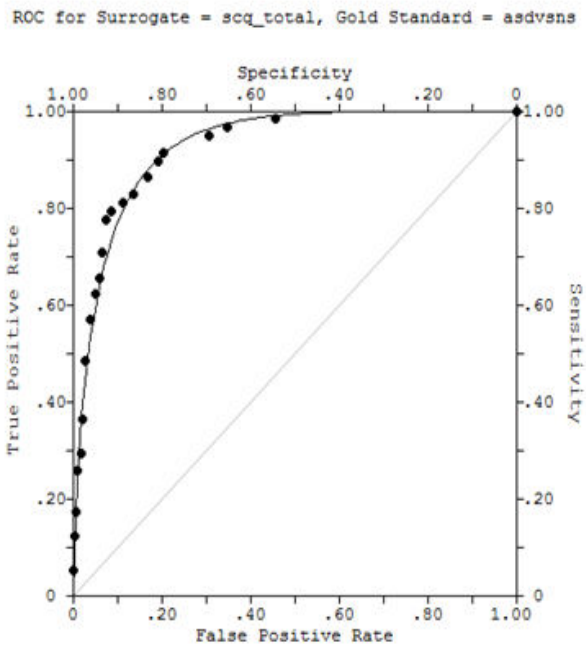
6.3.1 Differentiating ASDs from Other Developmental Disorders

The Area Under the Curve (AUC) was calculated to determine the performance of the SCQ for differentiating ASDs (all phenotypes) from other developmental disorders. The AUC was 0.9281 (95% CI: 0.8986 ± 0.9576). At the cut-off point recommended by Berument *et al.,* (1999) in the validation study (≥15) both sensitivity = 0.84 and specificity = 0.86 were good, however the optimal cut off point was ≥ 13, see Table 46.

Table 46: Discriminant Validity of the SCQ for National School Children: ASDs vs. Other Developmental Disorders

Optimal Cut Off	Sensitivity	Specificity	PPV	95% CI	PPV Odds Ratio	NPV	95% CI	NPV Odds Ratio
> =13	0.8965	0.8073	0.4333	0.3481 ± 0.5227	4.65	0.9794	0.9557 ± 0.9905	0.1281

Other Cut Offs	Sensitivity	Specificity
> = 12	0.9124	0.7936
> = 14	0.8789	0.8303
> = 15	0.8373	0.8625
> = 20	0.6409	0.9391
> = 22	0.5455	0.958



Two percent (n =10) of parents of children enrolled in national schools, with a parent reported diagnosed disorder, stated the child did not have language. There were no significant differences in scores between those with 9.38 (7.9) and without language 10.90 (10.25) $t(405) = -5.095$, $p > 0.05$.

6.3.2 Gender Differences in Discriminant Validity

There were no significant differences in SCQ scores for male and female children with an ASD diagnosis: Males, mean 21.78 (sd=6.03), Females, mean 20.23 (sd=7.36) $t(56) = 0.750$, $p > 0.05$.

Receiver Operating Curves were prepared by gender for differentiating ASDs from other developmental disorders. The AUC was marginally higher for males = 0.93 than for females 0.92. The optimal cut off score for males ($\geq$ 14) providing excellent sensitivity of 0.90 and good specificity of 0.82. The optimal cut off for females was ($\geq$ 13) which also provided good sensitivity of 0.88 and specificity of 0.80.

Table 47: Diagnostic Discrimination of Developmental Disorders for National School Children by Gender

Gender	N	Mean (SD)	Indo t test	Cut off	AUC	Sensitivity	Specificity
Males							
ASD	45	21.78 (6.31)	13.598 **	($\geq$ 14)	0.907	0.9026	0.8242
Other Diagnosis	248	7.63 (6.44)					
Females							
ASD	13	20.23	7.708 **	($\geq$ 13)	0.9248	0.8815	0.8097
Other Diagnosis	105	6.92					
$p < 0.05$ *							
$p < 0.001$ **							

6.3.3 Age Differences in Discriminant Validity

There were marginally significant differences in scores by age group $F(2) = 3.372$, $p = 0.042$ that were lowest for children in the 6-7 age bracket, and highest for those in the 8-9 year bracket.

For children in the 6-7 year, and 10-11 year age groups the optimal score for differentiating ASDs from other developmental disorders (≥ 14) however those in the 8-9 year age group required a higher cut off score (≥ 16) to achieve optimal sensitivity and specificity, see Table 48.

Table 48: Diagnostic Discrimination of Developmental Disorders for National School Children by Age Group

Age Group	N	Mean (SD)	Indo t test	Cut off	AUC	Sensitivity	Specificity
6-7 Yrs							
ASD	25	21.24 (6.73)	8.708**	14 +	0.9028	0.8712	0.7971
Other Diagnosis	116	8.35 (6.70)					
8-9 yrs							
ASD	19	24.00 (6.86)	12.565 **	16 +	0.9773	0.9522	0.9155
Other Diagnosis	130	6.85 (5.65)					
10 - 11 yrs							
ASD	14	18.29 (7.06)	6.174 **	14 +	0.8815	0.7685	0.8237
Other Diagnosis	107	7.09 (6.29)					
* P < 0.05, ** p < 0.001							

6.4 Item Analysis

Item analysis was performed using Chi Square tests to identify SCQ questions that differentiated autism spectrum disorder from other developmental disorders among national school children with a parent reported diagnosis. These findings will be explored for each of the three domains: Communication, Reciprocal Social Interaction and Restricted, Repetitive and Stereotyped Patterns of Interest.

Overall 89% (32/36) of SCQ ADI-R based questions significantly differentiated ASDs from other developmental disorders. The following items were identified which did not significantly differentiate ASDs from other developmental disorders. These will be discussed further in terms of the ADI-R domains, see Table 49.

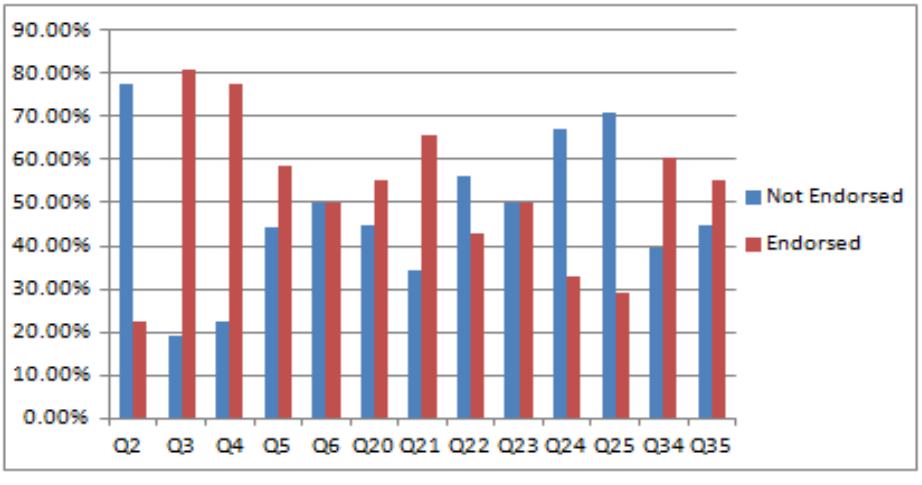
Table 49: SCQ Questions That Did Not Significantly Differentiate ASDs vs. Other Diagnosis for National School Children

Question	Chi Square
Q9. Inappropriate facial expression	2.063
Q22. Pointing to express interest	3.651
Q23. Gestures	0.386
Q25. Shaking head to mean no	2.504

6.4.1ADI-R Communication Domain

Seventy eight percent (13/10) of SCQ questions developed based on the Communication domain of the ADI-R, effectively differentiated ASDs from other developmental disorders. The following questions were not endorsed as autism positive in high frequencies by parents of children with a diagnosis of autism spectrum disorder: Q2 Conversation 22%, Q22 Pointing to express interest 43%, Nodding head to mean yes 33%, shaking head to mean no 30%, see Figure 19.

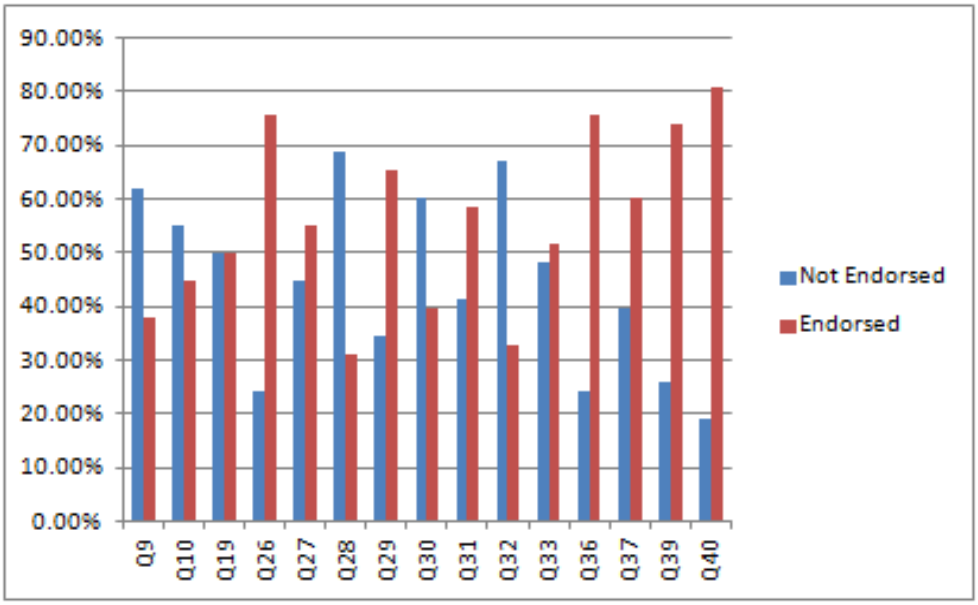
Figure 19: SCQ ADI R Communication Domain Questions (Endorsed / Not Endorsed) by Parents of National School Children with an ASD Diagnosis



6.4.2 ADI-R Reciprocal Social Interaction (RSI) Domain

Ninety three percent of SCQ questions (15/14) developed based on the Reciprocal Social Interaction domain significantly differentiated ASDs from other developmental disorders. The following questions were infrequently endorsed by parents of children with ASD diagnosis Q9 Inappropriate facial expression 38%, Q28 Showing and directing attention 31%. Q30 Seeking to share enjoyment 40% and Quality of social overturns 33% see Figure 20.

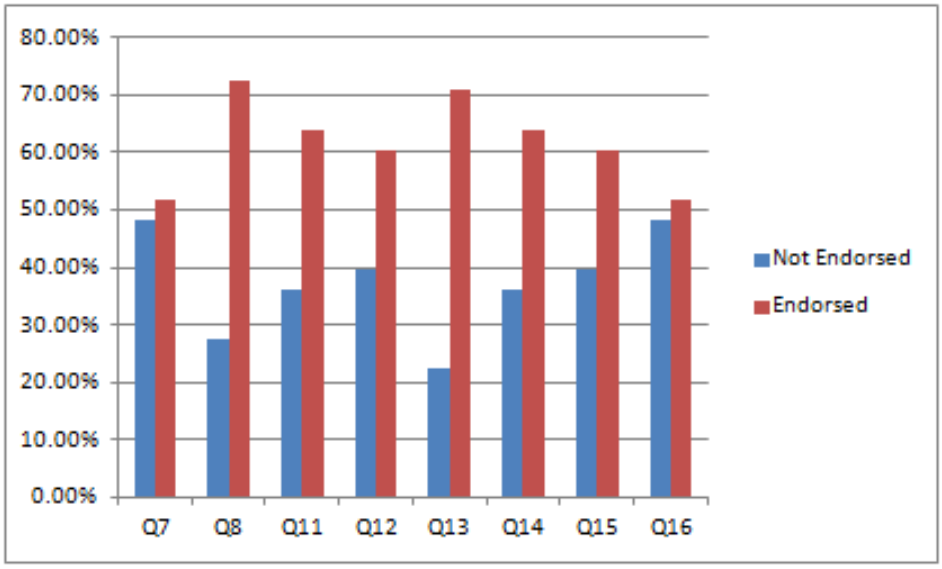
Figure 20: SCQ ADI R Reciprocal Social Interaction (RSI) Domain Questions (Endorsed / Not Endorsed) by Parents of National School Children with an ASD Diagnosis



6.4.3 ADI-R Restricted Repetitive & Stereotyped Patterns of Behaviour (RRSB) Domain

All questions based on the RRSB ADI-R domain significantly differentiated ASDs from other neuropsychological disorders and were endorsed in high frequencies by parents of children diagnosis on the autism spectrum, see Figure 21.

Figure 21: SCQ ADI R Repetitive Stereotyped Behaviour and Patterns of Interest (RRSB) Domain Questions (Endorsed / Not Endorsed) by Parents of National School Children with an ASD Diagnosis



6.4.4 ROC Analysis Based on Item Analysis Findings

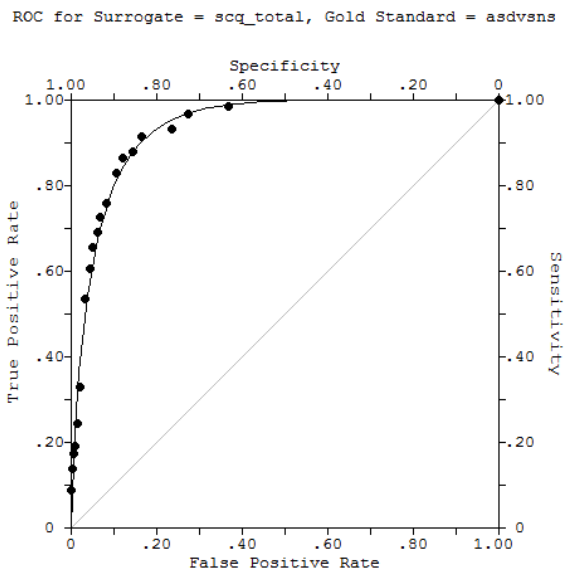
In summary ninety percent of SCQ questions (33/39) significantly differentiated ASDs from other diagnosis. The SCQ total score was recalculated after removing the four non-predicative item (pointing to express interest, gestures, head shaking to mean no, inappropriate facial expression) to explore improvements in sensitivity and specificity.

Removing questions that did not differentiate ASDs from other developmental disorders resulted in decreased sensitivity from 0.89 to 0.87, increased specificity from 0.80 to 0.85 at the optimal cut off (≥ 13). There was only a marginal improvement in positive predictive value from 0.43 to 0.50, and the negative predictive value remained the same, see Table 50.

Table: 50 Discriminant Validity of the SCQ for National School Children: ASDs vs. Other Developmental Disorders, Recalculated SCQ Total Score

Optimal Cut Off	Sensitivity	Specificity	PPV	95% CI	PPV Odds Ratio	NPV	95% CI	NPV Odds Ratio
≥ =13	0.8793	0.8555	0.5000	0.4047 ± 0.5952	6.086	0.9773	0.9539 ± 0.9889	0.1410

Other Cut Offs	Sensitivity	Specificity
> = 12	0.9055	0.8294
> = 14	0.8461	0.8742
> = 15	0.8164	0.8896
> = 20	0.5872	0.9531
> = 23	0.3452	0.9814



7.0 Discussion

First the utility of the SCQ was explored for differentiating ASDs from children identified with and without developmental disorders. The optimal cut off score was (≥12) below that recommended by Berument *et al.*, (1999) (≥15) providing sensitivity 0.91 and specificity 0.92. The parents of all children who scored 12 or more were followed up, whether or not they reported developmental disorders to re-administer the SCQ and confirm consent to access psychological and multidisciplinary assessments. This was an important component of the screening protocol for the identification of children who required ADOS/ADI-R and those who required multidisciplinary assessments. Although sensitivity and specificity were high positive predictive value was low, indicating that only 12% of high scores (≥13) were likely to be predictive of an ASD diagnosis. Negative predictive value was high 99% indicating that the majority of children with scores in this range who had not been flagged as having an ASD diagnosis were unlikely be at risk of an autism spectrum disorder.

The objective of further analysis was to explore the utility of the SCQ to differentiate ASDs from other developmental disorders. The utility of instruments developed to screen for autism spectrum disorders have been primarily validated from clinical samples of referrals not directly in community settings. Population screening studies using the CAST and ASSQ have been hampered to low response rates ~26%. To my knowledge this is the first study to clinically assess the utility of a screening instrument in a community setting of national school children obtaining high overall response rates ~70%.

The optimal cut off score for differentiating ASDs from other developmental disorders was (≥ 13) which is below that recommended by Berument *et al.,* (1999) the sensitivity of 0.89, and the specificity of 0.81 were acceptable, while the positive predictive value was, as expected, higher among this sub group of children at 43%, with negative predictive value at 97%. There were significant differences in scores by age but not for gender. Children in the 6-7 age brackets obtained the lowest scores, and the highest were in the 8-9 year bracket, scores were higher for males, than for females. A slightly lower optimal cut off score was suggested for females (≥13) than males (≥14) to achieve optimal sensitivity and sensitivity.

In their original validation study Berument *et al.,* (1999) performed item analysis and reported that 85% of the items differentiated ASDs from other developmental disorders. Items which did not included: stereotyped utterances, inappropriate questions, pronoun reversal and neologisms. Self-injury and unusual attachment to objects were only significant at the 5% level.

In this study ninety percent of questions differentiated children with autism spectrum from other developmental disorders. Those that did not were as follows: Q9 Inappropriate facial expression Q22 pointing to express interest, Q23 gestures, Q25 shaking head to mean no and which were different to those identified in the validation study. Excluding these questions from the total SCQ score had limited impact on the PPV / NPV performance of the SCQ for differentiating between children with ASDs from other developmental disorders.

Comparing the findings of the national school samples with previous studies the reported sensitivity was similar to that of Berument *et al.,* (1999), but at their recommended cut off point of 15 or over, the specificity obtained in the current study was higher at 0.86 vs. 0.75. In the current study sensitivity and specificity values were also higher than those reported by Corsello *et al.,* (2007) and Chandler *et al.,* (2007). Charman *et al.,* (2007) reported higher sensitivity at 0.90, while the specificity at 0.86 was the same as reported in the current study. At and above the recommended 15 + the cut-off point 50% of the children who were identified had a diagnosis other than autism spectrum disorder. The majority of these children misidentified, but with high scores identified had a diagnosis of ADHD, speech and language difficulties, dyspraxia and Downs's Syndrome.

This suggest that future studies will need to allocate resources for further assessments, for example the ADOS and the ADI-R. These are costly in terms of the time required to carry them out, and the cost of employing clinicians experienced in the use of these instruments. In the current study mean scores for children with autistic disorder 22.14 (5.74) were somewhat lower than those reported by Berument *et al.,* (1999) 23.08 Charman *et al.,* (2007) 25.80 and Chandler *et al.,* (2007) 26.6. One explanation for the lower scores observed is that children in the current study were enrolled in mainstream schools and may be higher functioning in terms of cognitive and adaptive behaviour compared to these studies.

In Chandler's study children were identified through the SNAP cohort study, and 55% of those with a diagnosis of ASD, and 73% of the most narrowly defined autism cases had IQs under 70 (Baird *et al.,* 2006). Berument *et al.,* (1999) reported that 67% of their children with a diagnosis of autism had an IQ under 70. The majority of the children in Charman's sample, 63%, had IQs over 70.

Scores for children with other ASDs 21.20 (6.80) were higher than reported by Berument *et al.,* (1999) 17.06; Charman *et al.,* (2007) 19.20; Chandler *et al.,* (2007) 19.6 and Corsello *et al.,* (2007) 20.26. On abstracting psychological and multidisciplinary assessments the majority of clinicians had simply recorded the child's diagnosis as 'autism spectrum disorder' as opposed to assigning more specific diagnoses such as autistic disorder and Asperger syndrome. As a result specific diagnoses on the spectrum could not be compared as part of our evaluation of the SCQ.

Corsello *et al.,* (2007) reported that younger children had lower scores among both clinical and research referred children needing a comprehensive assessment for autism spectrum disorder. In their study a wider age range was screened (2- 16 years) in comparison to the current study, which screened children in relatively restrictive age range from 6-11 years of age.

Data in the current and other studies reviewed is cross sectional, biases resulting from age of referral for assessments and means of recruitment (research vs. clinical) may have influenced scores.

Studies that screened preschool aged children were unable to obtain good sensitivity and specificity at the recommended cut off (15+) or at other cut off points to optimise these values. In the studies reviewed children's ages ranged from 1-6 years of age. Evans's Wingert, Ho and Mickelson (2006) explored the performance of the SCQ 11 + cut off in a preschool clinic sample sensitivity increased from 71% to 86% but specificity decreased from 76% to 53%.

Allen *et al.,* (2007) reported a cut off score of 11+ provided optimal sensitivity 93% but very poor specificity 58% low sensitivity yields many false positives which may cause increased parental anxiety whilst awaiting a formal diagnosis and the over burden on tertiary referral systems. The primary reason the SCQ is an effective screening instrument for young children in the fact that almost ½ of the questions relate to when the child was 4-5 years of age. These questions may also pose problems for screening older children as a result of reliance of retrospective parental recall to answer these questions.

Lee *et al.,* (2007) argued that the dependency on empirically derived cut off points underscores the challenges of assessing an ASD screener's performance for clinical applications, and the premium a particular clinician places on sensitivity/specificity can vary depending on the setting and circumstances. False positives may be of less concern when the clinician knows patient's will be under frequent follow up, while false positives may be less troubling when the clinician knows that the patient population is one where high prevalence of other developmental issues or co morbidities are likely to lead to frequent referrals for intensive evaluation.

In conclusion, although sensitivity and specificity was high for differentiating children with ASDs from those with and without other developmental disorders, the positive predictive value was very low at 12% indicating only a minority of children screened who obtained scores at or above the optimal cut-off ($\geq$13) would be correctly classified, indicating that many of the positive test results are in fact false positives. The main strength of the SCQ was the high negative predictive value 99% which indicates that when the SCQ yields a negative result it is likely to be correct.

Both sensitivity and specificity were also high for differentiating children with an ASD from other developmental disorders which is effectively how the screen is used in a clinical setting. The positive predictive value of the SCQ was higher at 41% at the optimal cut off ($\geq$13) indicating better test accuracy when used in a clinical context as opposed been used a population screening instrument, the negative predictive remained high at 98%.
The SCQ proved to be a more effective screening instrument when used for differentiating children with ASDs from other developmental disorders, as opposed to identifying children with an ASD diagnosis from those with and without other developmental disorders.

CHAPTER 9
THE SOCIAL COMMUNICATION QUESTIONNIARE DISCRIMINANT VALIDITY FOR SPECIAL EDUCATION SCHOOL CHILDREN

1.0 Introduction

In this chapter we will report on the ability of the SCQ to discriminate between children with and without diagnosed ASDs attending special schools. This group closely resembles the study populations in many previous studies of the SCQ (e.g. Berument *et a1.,* 1999) which have largely been carried out on clinical populations.

A summary of the studies that used the Social Communication Questionnaire (SCQ: Rutter et al., 2003) as a screening instrument were briefly discussed in Chapter 6. The psychometric properties of the SCQ were discussed in detail for school aged children in the Chapter 1 Literature Review – Section 4.

2.0 Study Methodology

The study methodology has been described in detail in Chapter 2.

3.0 Statistical Analysis

The primary objective of performing Receiver Operator Curves (ROC) analysis for children enrolled in special education schools was to evaluate the discriminant validity of the SCQ for differentiating autism spectrum disorder from other developmental diagnosis.
A series of receiver operating curves (Hanley & McNeil, 1982; Fombonne, 1991) were computed with MedRoC™ software, using a bivariate normal model. The area under the curve serves as an index of diagnostic accuracy (Berument *et al.,* 1999). Independent t tests were performed (Chapter 6- for Special Ed Schools) to identify SCQ items that differentiated autism spectrum disorders from other developmental disorders. The ROC analyses were repeated using the recomputed SCQ score (which excludes items that did not differentiate ASDs from other disorders) to explore the sensitivity and specificity, to define optimal cut off points for the identification of children with ASDs.

4.0 The Sample

The study population was 69 children aged 6-11 years, attending special schools, in Cork, Galway and Waterford. The overall response rate for this part of the study was very disappointing, with a 35% response rate. The majority were boys (50, or 73%) with 29 girls (27%).

A breakdown of diagnostic groups by gender is provided in Table 51. Almost all the study children had a parent report of a developmental disorder (68/69), including autism spectrum disorder. There were significant associations between diagnostic category and gender ($\chi 2$ (5) = 11.217, p > 0.05). Fifty two percent (n = 36) of children had a diagnosis on the autism spectrum disorder, males 92% (n =33) females 8% (n = 3)

Table 51: Neuropsychological Diagnosis of Special Education School Children by Gender

Neuropsychological Diagnosis	Gender					
	Male		Female		Totals	
	n	%	n	%	N	%
ASD	28	93.33%	2	6.67%	30	100.00%
Childhood Autism	5	83.33%	1	16.67%	6	100.00%
Cerebral Palsy	1	33.33%	2	66.67%	3	100.00%
Downs Syndrome	3	37.50%	5	62.50%	8	100.00%
Genetic Disorders	4	80.00%	1	20.00%	5	100.00%
Speech & Language	1	20.00%	4	80.00%	5	100.00%
Moderate to Severe ID	2	66.67%	1	33.33%	3	100.00%
Unspecified	6	66.67%	3	33.33%	9	100.00%

As explained in Chapter 2 – Study Methods, parental consent was requested to verify diagnosis from psychological assessments for children who obtained moderate (12-14) and high =15 SCQ scores. In the special education sample the parents of 10% (n = 7) of children who had obtained scores from 20 to 30 were excluded from the ROC analysis as the child's diagnosis was not reported in the study booklet, and consent to access psychological assessments was not provided.

The majority of parent reported diagnoses of ASD were confirmed through abstraction of psychological assessments 75% (n = 27) a breakdown of responses from the parents of these children is provided in Table 52. The validity of parent reported diagnosis for ASDs and other developmental disorders will be discussed in Chapter 6.

Table 52: Requesting Access to Psychological Assessments for Special Education School Children with a Parent Reported Diagnosis on the Autism Spectrum

Outcome of Contacting Parents	Special Schools	
	N	%
Parent confirmed access to psychological assessments	27	75.00%
Refused access to records by parents	4	11.11%
Refused access to records by clinicians	3	8.33%
Unable to contact parents	2	5.56%
Totals	36	100.00%

Psychological and multidisciplinary assessments were abstracted, with parental consent, to confirm parent reported diagnosis for all children who obtained moderate (12-14) and high scores (15+) on the SCQ. The majority of diagnoses were recorded as Autism Spectrum Disorder. There were an insufficient number of children assigned diagnoses of Asperger Syndrome, or Atypical Autism to explore the SCQs ability to differentiate between specific phenotypes on the autism spectrum and. There was also insufficient number of children diagnosed with an ASD to compare ROC curves by gender.

5.0 Diagnosed Disorders

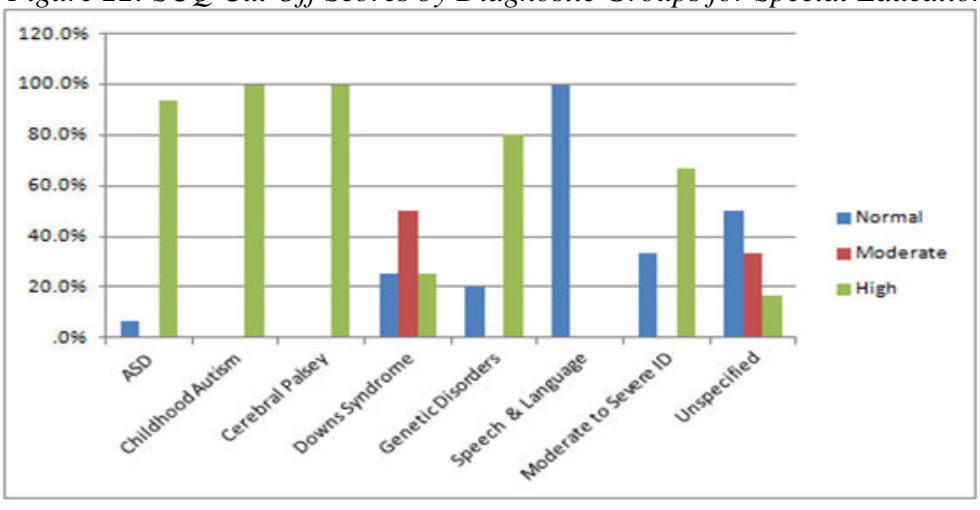
A total of 62 children were available for further evaluations. The mean total SCQ score for children with ASDs (mean, SD) 25.36 (6.875) was significantly higher than that for children with other diagnoses combined 15.46 (7.53); $t(60) = 5.375$, $p < 0.001$ and for the specific diagnostic groups $F(7) = 5.505$, $p < 0.001$. Children diagnosed with Childhood Autism (mean, SD) 28.33 (5.78) and other ASDs 24.77 (7.01) obtained the highest scores, followed by children diagnosed with genetic disorders and Cerebral Palsy, see Table 53.

Table 53: Descriptive Statistics for Special Education School Children Diagnostic Groups

Descriptive								
Neuropsychological Disorders	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
ASD	30	24.77	7.006	1.279	22.15	27.38	9	35
Childhood Autism	6	28.33	5.785	2.362	22.26	34.40	19	34
Cerebral Palsy	3	19.67	5.686	3.283	5.54	33.79	15	26
Down's Syndrome	8	15.38	8.450	2.988	8.31	22.44	4	29
Genetic Disorders	5	20.60	8.112	3.628	10.53	30.67	8	30
Speech & Language	1	9.00	.	.	.	.	9	9
Moderate to Severe ID	3	14.00	5.292	3.055	.86	27.14	8	18
Unspecified	6	11.00	6.033	2.463	4.67	17.33	2	20
Total	62	21.21	8.639	1.097	19.02	23.40	2	35

Ninety three percent (n = 28) of children with an ASD diagnosis obtained scores 15 + Childhood Autism 100% (n = 6). Many children diagnosed with Cerebral palsy 100% (n =6), and other Genetic disorders 80% (n = 4) also obtained scores at or above this cut off, see Figure 22.

Figure 22: SCQ Cut Off Scores by Diagnostic Groups for Special Education School Children



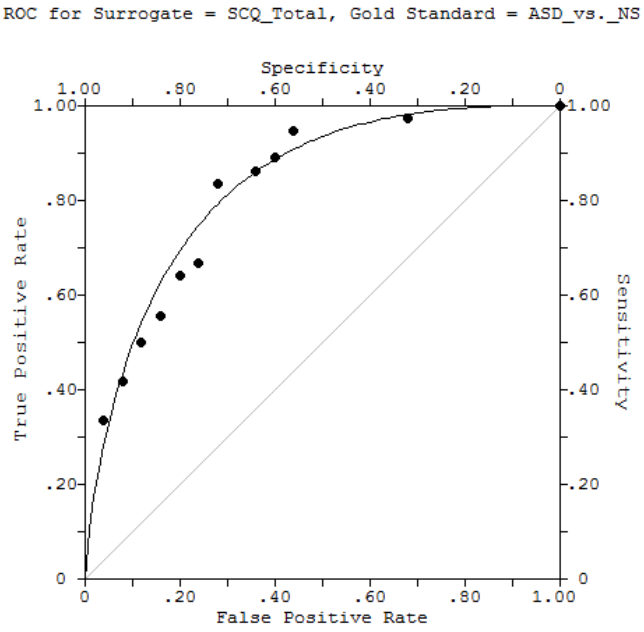
6.0 Receiver Operating Curves

6.1 Differentiating ASDs from Other Diagnosis

The area under the ROC curve (AUC) for the SCQ was 0.8329 (95% CI: 0.7278 ± 0.9380) for differentiating ASDs from other developmental disorders. An optimal cut off score could not be identified at the recommended cut off point = 15 sensitivity = 0.92, specificity = 0.53, or at higher cut off values, as the specificity remained high but sensitivity dropped considerably.

Table 54: Discriminant Validity of the SCQ Autism Spectrum Disorders vs. Other Developmental Disorders for Special Education School Children

Other Cut Offs	Sensitivity	Specificity
> = 13	0.9794	0.3248
> = 15	0.9223	0.5268
> = 22	0.6897	0.8010



6.2 Gender Differences in Discriminant Validity

Significant differences in scores were not observed by gender: males 21.79, (8.09) females 19.21 (10.41) $t(60) = 0.982, p > 0.05$, although the scores were marginally higher for males. Differences in scores were also not significant for the study child's place of birth - Irish: (mean SD) (21.00, 8.71) Non Irish: 22.86 (7.90) $t(60) = -5.33$, $p > 0.05$. Forty eight percent ($n = 30$) of parents reported the study child was not able to speak in short phrases or sentences, but there was no significant difference in SCQ scores for those with and (mean, SD) 20.43 (9.36) and without 22.36 (7.47) language $t(60) = -0.860$, $p > 0.05$.
There were insufficient numbers of cases of children with a diagnosis of autism spectrum disorder to explore the discriminative validity of the SCQ by gender.

SCQ questions are grouped into the three ADI-R domains: Communication, Reciprocal Social Interaction (RSI), and Restricted Repetitive Stereotyped Behaviour Domains, and the means for the three ADI-R domains were compared by gender. There were no significant differences in scores by gender for the three domains: Communication $t(60) = 0.707$, $p > 0.05$, RSI $t(60) = 0.246$ $p > 0.05$ and the RRSB $t(60) = 2.121$, $p > 0.05$ domain.

6.3 Age Differences in Discriminant Validity

Significant differences were not observed in scores by age group $F(2) = 0.921$, $p > 0.05$ see Table 55.

Table 55: SCQ Score by Age Group for Special Education School Children

Age Group	Mean	95% CI	SD	Std Error
6 - 7 yrs	22.00	17.43 ± 26.57	2.77	2.18
8 - 9 yrs	22.56	19.69 ± 25.43	7.25	1.39
10 - 11 yrs	19.14	15.53 ± 22.75	8.14	1.74

There were significant differences in mean scores across all age groups between children with an ASD diagnosis, and those with other developmental disorders, but an optimal cut off score with good sensitivity and specificity could not be identified for any age group.

Table 56: Diagnostic Discrimination by Age Group for Special Education School Children

Age Group	Cut Off	N	Mean (SD)	T	AUC	Sensitivity	Specificity
6-7 Yrs	14 +						
ASDs		10	26.30 (8.74)	2.148	0.7561	0.922	0.3781
Other Diagnosis		10	17.70 (9.15)				
8-9 yrs	16 +						
ASDs		14	26.21 (4.96)	3.152	0.8017	0.6429	0.7778
Other Diagnosis		13	18.62 (7.41)				
10 - 11 yrs	14 +						
ASDs		12	23.58 (7.32)	3.463	0.8554	0.9167	0.625
Other Diagnosis		10	13.80 (5.59)				
* $p < 0.05$							
** $p < 0.001$							

6.4 ROC Analysis Based on Item Analysis Findings

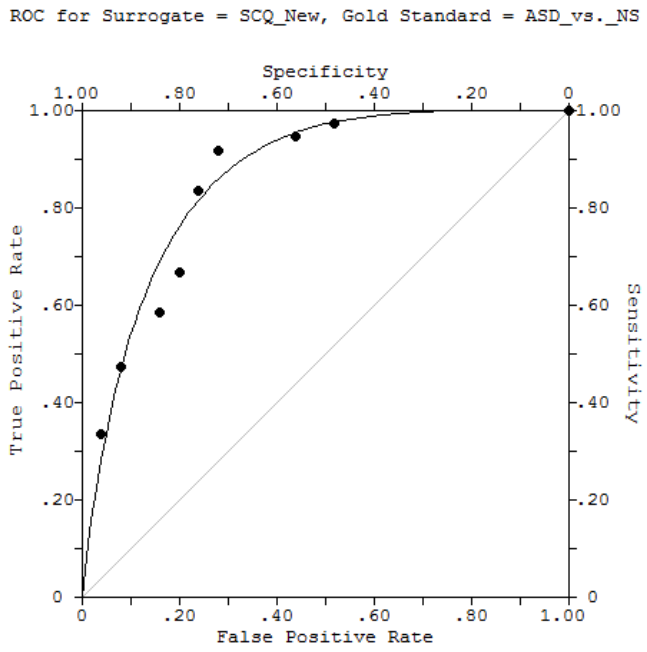
In Chapter 5 Chi Square tests were performed to identify SCQ items which significantly differentiated ASDs from other developmental disorders. ROC analysis was performed again recalculating the SCQ Total Score excluding 41% (n = 16) of questions that did not differentiate ASDs from other disorders, which have been discussed previously in Chapter 5.

Removing these questions improved sensitivity and specificity considerably identifying an optimal cut off score (≥13) providing sensitivity 0.83, specificity 0.76, positive predictive value was high among this at risk group of children screened indicating 83% of children with a positive test finding are at risk of an ASD, while 76% of children with a negative test finding will not be at risk of an ASD.

Table 57: Discriminant Validity of the SCQ Autism Spectrum Disorders vs. Other Developmental Disorders for Special Education School Children

Optimal Cut Off	Sensitivity	Specificity	PPV	95% CI	PPV Odds Ratio	NPV	95% CI	NPV Odds Ratio
13 >=	0.8333	0.7600	0.8333	0.6810 ± 0.9212	3.47	0.7600	0.5657 ± 0.8850	0.219

Other Cut Offs	Sensitivity	Specificity
> = 11	0.8899	0.6811
> = 15	0.688	0.8394
> = 19	0.3289	0.9509



7.0 Discussion

It was not possible to identify an optimal cut off point with optimal sensitivity and specificity for differentiating ASDs from other developmental disorders without excluding 40% of questions in the calculation of the total score. Recalculating the SCQ score excluding these questions provide optimal sensitivity 0.83, specificity 0.76 using a cut-off point of (≥13) whereby (PPV) 83% of autism positive cases were likely to be correctly identified and (NPV) 76% of negative screening results were likely to be correct.

The poor performance of the SCQ is likely to be the result of the low parental response rate 36% whereby the parents of lower functioning children appeared to be were inclined to complete the SCQ. The parents of these children may have been of the belief that their child had an Autism Spectrum Disorder as a secondary diagnosis, as abstraction of clinical data identified three additional cases of ASD that were not reported by parents as the primary diagnosis when fieldwork was undertaken.

Although this was a clinical sample of children the findings are not comparable to Berument's *et al.,* (1999) validation study given the small sample of parental returns, children in different diagnostic groups mean SCQ scores were higher for Autistic Disorder 24.77 vs. 23.08, other ASDs 24.77 vs. Atypical autism 17.03, Asperger Syndrome 7.03 and Down's syndrome 15.38 vs. 8.04. Children with genetic disorders 20.60 and Cerebral Palsy 19.67 who also obtained high scores were not included in the validation study.

Given the poor response rate from parents there was insufficient data to determine the effectiveness of the SCQ as screening instrument among this sample of school aged children with developmental disorders including autism spectrum disorder. However, the effectives of the SCQ has been explored among similar age groups of children who were referrals for autism screening in studies by Corsello *et al.,* (2007), Charman *et al.,* (2007) and Chandler *et al.,* (2007). The general findings from these studies was that the SCQ proved to be effective at differentiating ASDs from other developmental disorders, but was least effective at differentiating between different phenotypes on the autism spectrum.

Although the fieldwork protocol in this study was effective for screening national school children it was not effective with the special education cohort. A more effective screening protocol would have been to request written consent to access the records of eligible children without the necessity of parents having to complete the study booklet. It is expected that this approach would have resulted in significantly high response rates from parents to participate in the study.

CHAPTER 10
THE SOCIAL COMMUNICATION QUESTIONNAIRE
TEST RE TEST RELIABILITY
NATIONAL & SPECIAL EDUCATION SCHOOL CHILDREN

1.0 Introduction

The test-retest reliability of the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) has received little attention. There is only one published study by Bolte *et al.,* (2008) which examined the test re test reliability of the German SCQ adaptation in a sample of 136 individuals with autism 24% (n = 32), and other developmental disorders 76% (n = 104), with a mean age of 14.1 years. The Cronbach's alpha in the ASD sample was r = 0.83, and the test retest reliability over an interval of 6 months to 2 years, in a sub sample of 43 individuals (31 with ASD and 12 other clinical cases) was r = 0.76.

Other major studies using the SCQ have not assessed the test-retest reliability, including the original validation study by Berument *et al.,* (1999) nor studies in clinical samples of school aged children (Charman *et al.,* 2007; Chandler *et al.,* 2007; Corsello *et al.,* 2007) referred for ASD assessments; nor those in preschool children 3-6 years of age (Howlin & Karpf 2004; Lee *et al.,* 2007; Evans *et al.,* 2006; Allen *et al.,* 2007; Wiggins *et al.,* 2007; Snow *et al.,* 2008; Oosterling *et al.,* 2010).

A number of other autism related rating scales have had the test-retest reliability estimated, although mostly in clinical populations. The only exception we can identify is the study of Williams *et al.,* (2006) who reported the test re test reliability of the Childhood Autism Rating Scale (CAST: Scott *et al.,* 2002) for a subsample of (n = 136) children screened from a population of 1,000 school children 1-6 years of age. The test re test reliability was reported over a three week interval for the sub sample was a kappa of 0.82 across three score groups < 11, 12-14, 15+. A correlation of r = 0.83 (Spearman Rho) was reported and a Kappa statistic of 0.70 for cut off scores < 15 versus > 15. Just over 97% of children did not move across score groups.

The test re test reliability of the Autism Spectrum Screening Questionnaire (ASSQ: Ehlers & Gillberg., 1999) was explored by the authors from a sample of (n = 100) 6 -17 year old children with various behavioural disorders referred to a state wide child neuropsychiatric clinic over an 8 week period. Twenty percent (n = 21) of these children had a diagnosis of autism spectrum disorder. Two test re test reliability over a 2 week period for teacher ASSQ total score was r = 0.94, n = 86, p < 0.001, and parent scores r = 0.96, n = 86, p < 0.001. The mean test re test differences between parent-teacher assessments at Time I Time II was not significant.

Constantino, Prezbeck *et al.,* (2000) reported the test re test reliability of the Social Responsiveness Scale (SRS: Constantino & Gruber, 2005) acquired through teacher reports for (n = 287) school children and parent reports of Reciprocal Social Behaviours (RSBs) in (n = 158) child psychiatric patients 4-14 years of age. Stability of SRS scores was obtained for (n = 30) clinical subjects (average interval between assessments, 137 days; minimum 30 days) Pearson's r = 0.88. This sub sample consisted of non autistic patients with PDD-NOS (n = 9) r = 0.54 and child psychiatric patients with a variety of non-PDD diagnosis (n = 13) r = 0.62 and patients with Asperger disorder (n = 8, r = 0.72).

Constantino *et al.,* (2009) obtained assessments of (n = 95) epidemiological ascertained male-male twin pairs and a clinical sample of (n = 95) children 3- 18 years of age with a PDD diagnosis at two time points 1-5 years apart. A test re test correlation was only reported for the entire sample r = 0.90.SRS scores exhibited modest improvement over the study period.

2.0 Study Methodology

The study methodology has been described in detail in Chapter 2. The SCQ was re-administered to the parents of children (the majority of booklets were completed by mothers) who had obtained SCQ scores in the moderate (12-14) 4% (n = 225) and high (15+) score range 4% (n = 230). Only the parent who completed the booklet at TI was requested to recomplete the SCQ at TII. The primary objective was to identify children who scored in these score ranges who required referral for ADOS-G/ADI-R assessments. The SCQ was also re-administered to a stratified random sample of children 5% (n = 300) who scored in the normal range (Score range: 0 to 11). The sample was stratified by age, gender, class, and school type. The time period between administrations ranged from 3 months to 1 year 8 months.

3.0 Statistical Analysis

Paired sample t tests were used to explore mean differences between the three score groups (Normal, moderate, high) for children identified at Time I (TI) and Time II (TII) enrolled at national and special educations schools to identify children who moved between score groups. Mean Scores for children with no identified problems, those diagnosed with an ASD, and those with other developmental disorders were compared at TI and TII time points to explore significant differences between these groups.

Analysis was performed specifically for children with a confirmed diagnosis of ASD and other developmental disorders to explore movement between groups and evaluate differences in mean scores. Finally bivariate correlation coefficients for children with and without ASDs and other developmental disorders were reported for comparison with previous studies.

4.0 Results

The overall response rate from parents of study children who were asked to recomplete the SCQ was (66%) 499 in the three score groups out of 755 approached, see Table 58 with 69% of these scoring 0 to 11; 62% scoring 12 to 14, and 67% of those scoring over 15).

Table 58: Response Rates for the Parents of National School Children asked to Recomplete the SCQ

Score Group	**Asked to Participate**	**Responded**	**Response rate**
Normal 0-11	300	206	68.70%
Medium 12-14	225	139	61.80%
High 15 +	230	154	67.00%
Total	**755**	**499**	**66.10%**

4.1 Stability of Scores for National School Children

Mean scores at both time points TI and TII were compared for children across all score groups with and without a diagnosis of ASD and other developmental disorders. Scores were lower at TII across all groups. Significant differences were observed between scores for children who scored in the moderate and high groups, see Table 59.

Table 59: Mean Scores for Low, High, and Moderate Score Groups for National School Children at TI and TII

Score Group	N	Time 1			Time 2				
		Mean	SD	Mean 95% CI	Mean	SD	Mean 95% CI	Mean Difference	p-value
Low score	206	3.33	2.65	2.97 ± 3.69	3.3	3.6	2.80 ± 3.79	0.03	p > 0.05
Moderate score	139	12.86	0.83	12.72 ± 13.00	9.09	5.22	8.22 ± 9.97	3.77	p = 0.001
High score	154	20.08	4.80	19.32 ± 20.85	16.2	7.42	15.02 ± 17.39	3.88	p = 0.001

There was variability in scores for children with diagnosed disorder other than ASDs especially in the moderate score range, only 24% of scores remained in this score range. However 73% of high scores at Time 2 remained in this range, see Table 60.

Table 60: Movement between Score Groups (Normal, Moderate, High) for National School Children with Diagnosed Disorders (Excluding ASDs Cases)

	SCQ TII						Totals	
	< 11		12 - 14		15 +			
SCQ TI	N	%	N	%	N	%	N	%
< 11	3	75%	----------	----------	1	25%	4	100%
12-14	9	42.90%	5	23.80%	7	33.30%	21	100.00%
15 +	7	20.60%	2	5.90%	25	73.50%	34	100.00%

Seventy nine percent (n = 35) of children diagnosed with an ASD scored at or above the recommended cut off score (≥15)11% (n = 5) in the moderate and (n = 4) 9% in the normal score range. Ninety three percent (n = 13) of children diagnosed with Autistic Disorder scored at or above the recommended cut off score, 7% which only relates to one cases scored in the normal range.

Eighty six percent (n = 38) of parents with a child diagnosed with an ASD recompleted the SCQ. Only a small number of children were identified who scored in the normal and moderate score ranges, 93% of high scores for these children remained in this score range at TII, see Table 61.

Table 61: Movement between Score Groups for National School Children with an ASD Diagnosis

	SCQ TII						Totals	
ASD	< 11		12 - 14		15 +			
SCQ TI	N	%	N	%	n	%	N	%
< 11	2	50.00%	2	50.00%	----------	----------	4	100.00%
12-14	2	40.00%	1	20.00%	2	40.00%	5	100.00%
15 +	----------	----------	2	6.90%	27	93.10%	29	100.00%

Eighty five percent (n = 12) of parents of children with a diagnosis of Autistic Disorder recompleted the SCQ. Only a small number of children scored in the normal range on initial assessment, and no children scored in the moderate score range. Eighty two percent (n = 9) of scores remained in the high score range on re-administration of the SCQ, (n = 2) 18% of scores moved from the high to moderate range, see Table 62.

Table 62: Movement between Score Groups for Children with a Diagnosis of Autistic Disorder

	SCQ TII						Totals	
AD	< 11		12 - 14		15 +			
SCQ TI	N	%	N	%	n	%	N	%
< 11	1	100.00%	----------	----------	----------	---------	1	100.00%
12-14	------	----------	----------	----------	----------	----------	----------	---------
15 +	------	----------	2	18.20%	9	81.80%	11	100.00%

4.2 Movement of Scores for Children in the Normal Range

Sixty nine percent (n = 206) of the parent's children enrolled in national schools who scored in the normal range for the validation study re-completed the SCQ. The majority of scores for these children remained in the normal range (n = 199) 97%, with (n = 4) 2% moving in to the moderate score range and (n = 3) 1.5% into the high score range.

4.3 Scores for Children with and without Developmental Disorders

The characteristics of children followed up without a diagnosis, diagnosed with autism spectrum and other developmental disorders were explored to determine if there were statistically significant differences between scores at TI and TII. Statistically significant differences between scores between the two time points were not observed for children who did not have a diagnosis, or diagnosed with disorders. There were no significant differences in SCQ mean scores following up children in different diagnostic groups with and without a diagnosis of autism spectrum disorder, see Table 63.

Table 63: SCQ Scores Time I & II for National School Children Diagnostic Groups

	SCQ Time I		SCQ Time II			
Diagnostic Group	Mean	SD	Mean	SD	t test	P value
Parental Concerns, not Diagnosed	15.08	5.57	13.16	6.45	2.039	NS
ASD	21.13	7.25	19.95	6.36	1.644	NS
Autistic Disorder	21.5	5.97	19.42	6.93	1.278	NS
Other Developmental Diagnosed Disorders	16.51	5.71	15.44	6.65	1.46	NS

SCQ Scores for children in the three groups were explored further to determine if there were significant differences in scores by age and gender, significant differences were not observed for the three groups (no diagnosis, ASDs, other diagnosis).

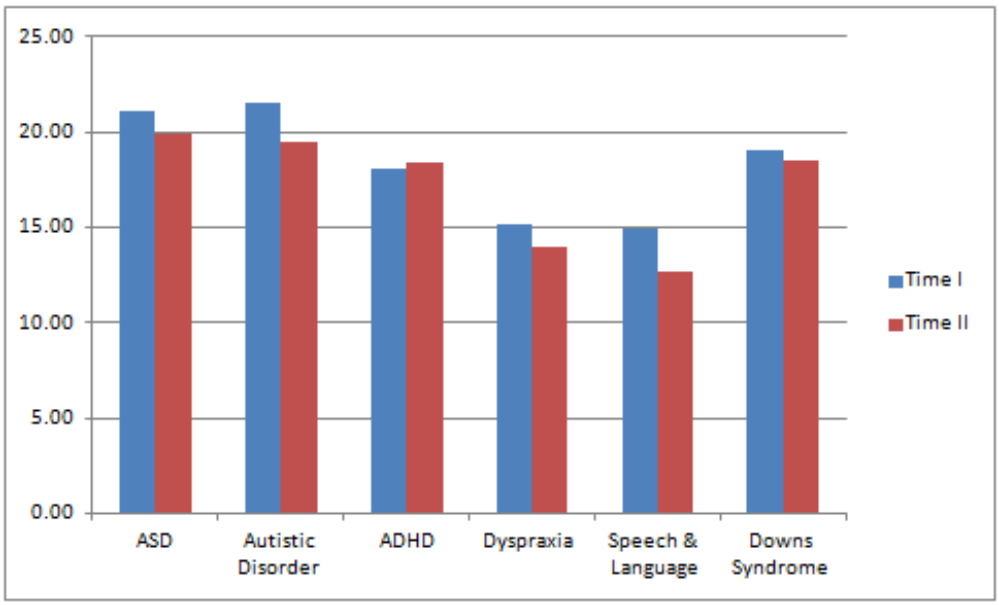
The Pearson correlation was relatively strong for all children $r = 0.77$, $n = 499$, $p < 0.001$ at the two time points. The findings for the three different diagnostic status groups are presented in Table 64 whereby the stability of scores at TI TII was greater for those with an ASD diagnosis compared to the other two groups.

Table 64: Persons Correlation Coefficients for National School Children Diagnostic Groups

Diagnostic Group	Pearson Correlation	p value
Parental Concerns, Not Diagnosed	0.43	$p < 0.001$
ASD	0.75	$p < 0.001$
Other Developmental Diagnosed Disorders	0.59	$p < 0.001$

There were no significant differences between confirmed diagnostic groups and scores at Time I and Time II using paired sample t tests. Scores for all diagnostic groups were lower at Time II apart from those for children with an ADHD diagnosis whereby scores at Time II 18.39 (5.13) were marginally higher than at Time I 18.06 (5.25), see Figure 23.

Figure 23: Mean Scores for Diagnostic Groups at Time I and Time II for National School Children



5.0 Special Education Schools Results

5.1 Stability of Scores for Special Education School Children

The SCQ was re-administered to the parents of 74% (n = 51) children who obtained SCQ scores in the normal, moderate and high score ranges. The majority of completed study booklets 94% (n = 48) for these children were filled in by their mothers.

Most of these children were male (76%, n = 39), and born in Ireland (88%, n = 45), and aged between 8 to 9 years (35%, n = 18), and 10 to 11 (35%, n = 35) year. The mothers who re-completed the SCQ were predominantly Irish (84%, n = 38), working as homemakers (61% n = 28), while a minority (28%, n = 13) reported that they were employees, or self-employed, working in equal numbers in professional, managerial technical, non-manual and skilled semi-skilled occupations. Only 16% (n = 8) of mothers reported they were educated to degree or graduate level.

Mean scores were compared across the three groups at both time points TI and TII. Scores increased at TI and TII for children followed up at special education schools that initially scored in the normal and high score ranges. However, the number of children in these groups was small. The majority of children who scored in the high range at T1 (15+) had lower scores at TII.

Table 65: Mean Scores for Low, High, and Moderate Score Groups for Special Education School Children at TI and TII

Score Group	N	Time 1			Time 2				
		Mean	SD	95% CI	Mean	SD	95% CI	Mean Difference	p-value
Low score	9	7.89	2.98	5.60 ± 10.18	12.67	5.48	8.46 ± 16.88	-4.78	p = 0.045
Medium score	3	13.00	0.577	13.67 ± 12.23	14.33	4.72	2.59 ± 26.07	-1.33	NS
High score	39	24.59	6.44	22.50 ± 26.68	22.95	6.89	20.72 ± 25.18	1.64	NS

Seventy percent (n = 23) of the parents of children males 61% (n = 14) females 39% (n = 9) diagnosed with developmental disorders other than an ASD recompleted the SCQ.
The number of children who initially scored in the normal (0-11) and moderate range (12-14) was low. There was more change over time than in the national school sample, particularly for children with scores in the low and medium range, see Table 66.

Table 66: Movement between Score Groups (Normal, Moderate, High) for Special Education School Children with Diagnosed Developmental Disorders (Excluding ASD Cases)

	SCQ TII						Totals	
Other Diagnosis	< 11		12 - 14		15 +			
SCQ TI	N	%	N	%	n	%	N	%
< 11	4	57.10%	1	14.30%	2	28.60%	7	100.00%
12-14	1	33.30%	----------	----------	2	66.70%	3	100.00%
15 +	1	7.70%	2	15.40%	10	76.90%	13	100.00%

Ninety three percent (n = 28) of children diagnosed with an ASD scored at or above the recommended cut off score of 15, only 7% (two children) scored in the normal range, 100% of children with a diagnosis of Autistic Disorder (n = 6) scored at or above the recommended cut off score of 15 or more.

Seventy eight percent (n = 28) of the parents of these children recompleted the SCQ. Owing to the small number of children with a diagnosis of Autistic Disorder (n = 5) followed up the movement of scores on re-administration of the SCQ will be explored for all ASD cases followed up. Only two children scored in the normal range at TI. One child's score remained in the normal range, while that of the other child moved up into the high (15+) score group. The majority of children who scored in the high score range 92% (n = 24) remained in this group at TII. Two children moved down score group into the moderate 3.8% and normal range 3.8% at TII, see Table 67.

Table 67: Movement between Score Normal, Moderate, High Score Groups for Special Education School Children with an ASD Diagnosis

	SCQ TII							
ASD Diagnosis	< 11		12 - 14		15 +		Totals	
SCQ TI	N	%	N	%	n	%	N	%
< 11	1	50.00%	---------	---------	1	50.00%	2	100.00%
12-14	---------	---------	---------	---------	---------	---------	---------	---------
15 +	1	3.80%	1	3.80%	24	92.30%	26	100.00%

5.2 Scores for Children with and without Developmental Disorders

No statistically significant differences in SCQ scores at Time 1 and Time 2 were observed for children with a diagnosis on the autism spectrum or other developmental disorders see Table 68.

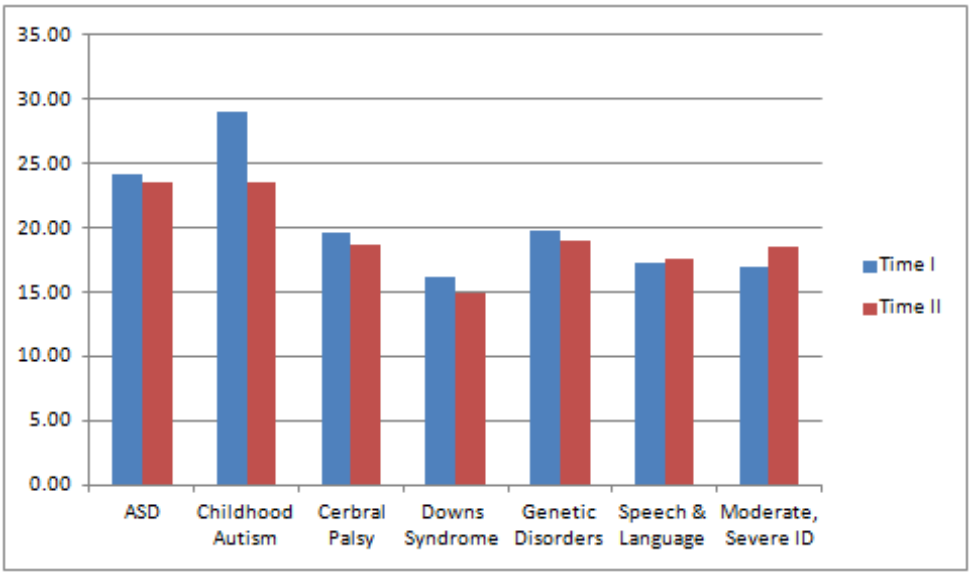
Table 68: SCQ Scores Time I & II for Special Education School Children by Diagnostic Group

	SCQ Time I		SCQ Time II			
Diagnostic Group	Mean	SD	Mean	SD	t test	P
ASDs	24.13	7.7	23.56	6.93	0.482	NS
Autistic Disorder	29.00	6.2	23.6	9.23	0.266	NS
Other Diagnosis	16.13	7.72	17.04	6.91	-0.78	NS

Pearson correlation coefficients were relatively strong at TI and TII r = 0.728, n = 51, p < 0.001 for all children followed up at the two time points who were enrolled at special education schools. Surprisingly the correlations for children with diagnosis other than autism spectrum disorder were stronger, r = 0.711, n = 23, p < 0.001 than for children with an ASD diagnosis r = 0.615, n = 28, p = 0.001. There were no significant differences in scores at Time II by age and gender for children with a diagnosis on the autism spectrum and other developmental disorders.

Statistically significant differences in scores were not observed between diagnostic groups at Time I and Time II using paired sample t tests. Scores at Time II were lower than at Time I for all diagnostic groups apart from children with a diagnosis of moderate to severe ID who scored 17.00 (1.41) at Time I and 18.50 (2.12) at Time II, and marginally higher for speech and language disorders Time I 17.33 (7.37) Time II 17.67 (9.86) see Figure 24.

Figure 24: Mean Scores for Diagnostic Groups at Time I and Time II for Special Education School Children



6.0 Discussion

The test re test reliability of the Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) was calculated for children who scored in the normal, moderate and high score ranges over a time period (mean time interval: 15 months). The parents of the majority of children were followed up at least 6 months after the SCQ was originally completed. A high percentage of parents of children enrolled at national schools recompleted the screening instrument at TII, 69% of parents contacted with a study child who scored in the normal range, 67% of children who scored in the moderate to high score range. The majority of study booklets were completed by mothers. It was essential to ensure the instrument was recompleted by the parent who originally completed the study booklet.

There is almost no test re test reliability data published on the SCQ, apart from a German study by Bolte *et al.,* (2008). They reported a Pearson correlation coefficient for all national school children followed up over a two week interval which was relatively high at r= 0.75 (with and without developmental disorders), which is comparable with the findings in this study for children with an ASD diagnosis. Children in the German study in the PDD group r= 0.83 correlation coefficients were stronger however they were reassessed over a short time period (2 weeks). Pearson correlation coefficients for children with an ASD diagnosis enrolled at special education schools r = 0.61 were weaker than the national school cohort.

Children with high scores diagnosed with autism spectrum and other developmental disorders identified through national schools may have been less impaired at TI and therefore more likely to demonstrate higher functioning overtime, so explaining the weaker correlation coefficients than the German study. The relatively long duration between re-administration of the screen is also a consideration as these children would have been receiving speech and language therapy and other interventions, possibly resulting in improved functioning over time.

Mean scores were lower on re-administration of the screen, but the difference were not statistically significant, for children identified at national and special education schools with and without a diagnosis of ASD and other developmental disorders, neither were the differences between score groups significantly different by age and gender.

Regression to the mean is one explanation for observed lower mean scores over time on re-administration of the SCQ. Other explanations must also be considered for example children with diagnosed developmental disorders including ASDs would have been receiving interventions either at school of privately over the 15 month period. There were significant differences in mother's social class, ethnic & cultural background, and level of education. A high percentage of high scores at Time 1 that were not observed at Time 2 especially for children who scored in the moderate score range may be explained by literacy and language difficulties. The parents of these children may have received assistance on completing the SCQ on the second occasion explaining the reduction of scores into the normal range.

As expected parents who completed the SCQ on children with initially normal scores, as part of the validation component of the study 98% of scores remained in the normal range. For children with moderate scores initially, on re-administration of the SCQ (excluding children with a diagnosis on the autism spectrum), only 13% of scores remained in the moderate score range, 71% dropped into the normal score range on re-administration. Of those with high scores initially, 50% of scores remained in the high score range, 39% moved into the normal and 12% moderate score range.

The majority of children with a diagnosis of ASD were identified at the recommended cut off score ($\geq$15) 79%. However, 11% of children with an ASD who scored in the moderate range and would not have been identified if they were not further screened below the recommended cut off. The majority of children 93% diagnosed with Autistic Disorder scored at or above the recommended cut off score. Only a small number of children in both the ASD and Autistic Disorder groups scored in the normal and moderate score range, the majority of these children scored in the high score range at both time points, 83% ASDs and 93% of cases of Autistic Disorder.

With regards to children identified with a diagnosis on the autism spectrum enrolled at special education schools 93% of ASDs and 100% of children with a diagnosis of Autistic Disorder scored at or above the recommended cut off score. Score were stable at this cut off with 94% of cases remaining in this range on re-administration of the SCQ.

In conclusion the SCQ was most effective at differentiating children with a clinical diagnosis of Autistic Disorder with only 7% of these children enrolled at national schools undetected at or above the recommend cut off score, 93% of scores in this range remained stable at both time points. Seventy nine percent of children diagnosed with an ASD were identified at the recommended cut off score, 83% of children remained in the high score range on re-administration of the SCQ.

The SCQ has demonstrated good test re test reliability in this study considering the relatively long duration between re testing. As expected the number of children identified at or above the recommended cut off score and stability of scores was higher for lower functioning children on the autism spectrum.

CHAPTER 11
THE SOCIAL COMMUNICATION QUESTIONNAIRE
FACTOR ANALYSIS
NATIONAL SCHOOL SAMPLE

1.0 Introduction

The Social Communication Questionnaire (SCQ: Rutter *et al.,* 2003) was developed primarily as a screening instrument for use in clinical settings. As part of a larger study using the SCQ, we wish to analyse the factor structure of the SCQ. Our study uses a large sample of children aged 6 to11, ascertained through primary schools, in three centres in the Republic of Ireland.

An earlier validation study of the SCQ was performed by Berument *et al.,* (1999) among a sample of (n = 200) individuals who were participants in previous studies. The background of this study was described in Chapter 1, Section 5. As part of this study, they carried out a factor analysis. Principal component factoring with varimax rotation yielded four factors which explained 42.4% of the total variation with 24.3% accounted for by a social interaction factor (eigenvalue 9.7), 8.7% by a communication factor (eigenvalue 3.38), 5% abnormal language factor (eigenvalue 1.94) and 4.5% by a stereotyped behaviour factor. The alpha reliability for the whole scale was 0.90; for the first factor 0.91, second factor 0.71, third factor 0.79, and fourth factor 0.67. All individual items to total score correlations were positive and most were substantial in the range 0.26 – 0.73 (23 of the 39 exceeding 0.50).

Magyer *et al.,* (2012) also investigated the psychometric properties of the SCQ in a sample of children with Down's syndrome 4- 14 yrs (n = 448) many of whom had co-occurring autism spectrum disorders. Questions relating to language (Q2 to Q7) were omitted as were Q32 (Quality of Social Overtures) and Q39 (Imaginative Play), so as to identify a factor structure for the remaining questions, for children with and without language. A 2 factor solution accounted for 54.4% of the variance. Factor 1 was named Social-Communication, which accounted for 39.9% of the variance; Factor 2 was labelled Stereotyped Behaviour and Unusual Interests.

In the two factor solution significant factor pattern coefficients were obtained for all items, and each factor contacted at least five items with coefficients >0.60, providing evidence of a stable structure for samples of smaller size (Guadagnoli, Velicer, 1988). A statistically significant factor correlation of 0.428 indicated that the factors shared 18.3% of the variance, suggesting that the SCQ measured 2 related but non redundant dimensions of ASD. CFA parameters were used to compute the scale reliabilities for the Social Communication and Stereotyped Behaviour and Unusual Interests factor based scales which yielded reliability coefficients of 0.96 and 0.83 respectively.

Empirical studies of the structure of autism symptoms have been inclusive (Constantino et al., 2004; Tadevosyan-Leyfer *et al.,* 2003; Lecavalier *et al.,* 2006). While some authors have explained a single factor to explain autism symptoms (Constantino *et al.,* 2004) other have proposed two to six (e.g. Lecavalier *et al.,* 2006; Georgiades *et al.,* 2007; Szatmari *et al.,* 2002; Tadevosyan-Leyfer *et al.,* 2003).

According to current diagnostic criteria autism is diagnosed when an individual exhibits qualitative abnormalities in each of the three symptom domains. Although the current diagnostic systems accurately identify classic autism it has been suggested that these criteria are not sufficient for capturing the variability in the clinical expression of autism (Tanguay, Robertson, & Derrick, 1998).

It is possible that the three domain conceptualisation of autism does not precisely describe the disorder, thus contributing to unreliable diagnosis. Several researchers have used the Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) to explore the autism phenotype. The findings from these studies are not entirely consistent with the behavioural domains of autism as defined by the DSM. Previous ADI-R factor analytic studies suggest substantial overlap in the social and communication domains and a decomposition of the restricted and repetitive behaviour domain into two dimensions (Tanguay *et al.,* 1998; Cuccaro *et al.,* 2003).

Snow *et al.,* (2009) also reported the autism phenotype was explained by a two factor model with social/communication symptoms and restricted and repetitive behaviours a two and three factor solution was similar but better than a one factor model, measures of internal consistency suggested a separate factor for repetitive behaviours.

The repetitive behaviour factor did not emerge as two dimensions (repetitive sensory motor and insistence on sameness) as reported by (Cuccaro *et al.,* 2003; Szatmari *et al.,* 2006).

Refining the structure of the autism phenotype has implications for the nosology / diagnostic practices and can provide valuable information for genetic research, which include revisions to diagnostic systems based on the combination of social and communication symptoms into one domain of impairment, and a need for a better understanding of the restricted/repetitive behaviours dimension of autism (Snow *et al.,* 2009).

2.0 Study Methodology

The study methodology has been described in detail in Chapter 2.

3.0 The Sample

Seven percent of the children whose parents completed a study booklet (n = 411) enrolled at national schools had a diagnosed developmental disorder (including Autism spectrum disorders).

4.0 Statistical Analysis

Cronbach's alpha was used to explore the reliability of SCQ questions as related to the total score prior to performing Principal Components Analysis (PCA), using promax rotation.

As the majority of SCQ questions were developed based on the ADI-R two (PCA) models were proposed to explore the component structure of the screening instrument:

- In Chapter 6 – Receiver Operator Curves were used to determine the optimal cut off score for identifying children with an ASD diagnosis from children with and without other developmental disorders. A cut off score at and above 12 was identified providing optimal sensitivity and specificity. These samples of children were identified for the 1st proposed PCA model.

- The 2nd proposed PCA model was to compare the component structure of the ADI-R based questions for children identified with diagnosed developmental disorders, including autism spectrum disorder.

It is highlight that the majority of studies which have explored the factor structure of the ADI-R have included relatively large samples of children with autism spectrum disorders, which only represented 14% of children identified with diagnosed developmental disorders. As such the findings from this study are exploratory and not directly comparable to previous ADI-R factor analytic studies. However the findings will be provide useful information with regards to the variability of how questions based on the ADI-R domain are represented as components in each of the proposed PCA models.

5.0 Principal Components Analysis

Principal component analysis is concerned with establishing which linear components exist within the data and how a particular variable might contribute to that component. It is a data reduction technique that maximises the amount of variance accounted for in the observed variables by smaller group of variables called components. A matrix represents the relationship between variables and cases. Linear components of that matrix are calculated by determining the eigenvalues of the matrix. These eigenvalues are used to calculate eigenvectors, the elements that provide the loadings of a particular variable. Not all factors are retained in the analysis, only those with large eigenvalues are retained. Kaiser (1960) recommended retaining all factors with eigenvalues greater than 1. Jolliffe *et al.,* (1972, 1986) reported that Kaiser's criterion is too strict and suggested retaining all factors with eigenvalues more than 0.7.

Once factors have been extracted it is possible to calculate the degree to which individual variables load onto these factors/components. If a factor is a classification axis along which variables can be plotted, factor rotation effectively rotates these factor axes such that variables are loaded maximally to only one factor. By rotating the axis we ensure that clusters of variables are intersected by the factor to which they relate most. After rotation the loadings of the variables are maximised onto one factor and minimised on the remaining factors. There are two types of rotation orthogonal and oblique. In the former technique the factors are rotated while keeping them independent in the latter technique they are allowed to correlate. Methods of orthogonal rotations include (varimax, quatimax, and equamax) and oblique rotation (direct oblimin and promax).

Once a factor structure has been found it is important to decide which variables make up which factors, factor loadings are a gauge of the substantive importance of a given variable to a given factor. Steven's *et al.,* (1992) recommended interpreting factor loadings with an absolute value greater than 0.4. However, the significance, or otherwise, of a factor loading is dependent on the sample size. Principal components analysis is a psychometrically sound procedure, and conceptually less complex than factor analysis (Field, 2005). Guadagnoli & Velicer (1988) concluded that the solutions generated from principal components analysis differ little from those derived from factor analytic techniques.

6.0 Results

6.1 Internal Consistency

Cronbach's alpha was calculated to determine the reliability of the SCQ. It is related to the mean correlation between each pair of questions and the number of questions in the screening instrument. A scale should have a minimum alpha value of 0.7. Even if a scale has a high alpha individual items may be poorly correlated with others (Brace, Kemp, Snelgar, 2006). Corrected item total correlations are correlations between each question and the total score from the questionnaire. In a reliable scale all items should correlate with the total, any items with values less than 0.3 (dependent on sample size, with larger samples smaller correlations are acceptable) do not correlate well with the scale overall and should be considered to be removed from the scale (Field, 2005).

In the first proposed PCA model the Cronbach's alpha was calculated for children identified at and above the optimal cut off score of 12 (n = 455) males (n = 303) 67%, females 33% (n = 152), 44% (n = 199) of these children had a developmental diagnosis. The majority of children with a diagnosis of ASD (n = 40) 91% were identified at this cut off point, and 93% (n = 14) with a diagnosis of Autistic Disorder.

However a Cronbach's Alpha of 0.627 was obtained for the total score (n = 39 items) and the majority 74% (n=29) of inter item correlations for individual questions with the total score was below 0.3 which is unacceptably low. As a result of these findings a PCA model was not performed.

The alpha value was high for children identified with parent reported developmental disorders (including ASDs) (n = 39 items) α= 0.915. Corrected item total correlations were relatively poor for the questions in Table 69.

Table 69: Poorly Correlated Corrected Item Total Correlations for National School Children with Diagnosed Learning Disabilities

Question	SCQ ADI-R Domains	Corrected Item Total Correction
Q2. Conversation	Communication	0.196
Q9. Inappropriate Facial Expressions.	RSI	0.071
Q19. Friends	RSI	0.281
Q21. Imitation	Communication	0.215
Q22. Pointing to express interest	Communication	0.286
Q23. Gestures	Communication	0.254
Q24 Nodding head to mean yes	Communication	0.236
Q25. Head shaking to mean no.	Communication	0.205

The questions in Table 1 were therefore excluded from the Principal Components Analysis. Cronbach's alpha for the remaining SCQ (n = 31) questions was increased to α= 0.928, and the corrected item total correlations for the remaining (n = 31) variables were all greater than 0.3.

6.2 Adequacy of Factor Analysis

The Kaiser-Mayer-Olken measure of sampling adequacy was 0.922 indicating a good structure for factor analysis. To access the goodness of fit of the model we can look at the correlations between the observed correlations and those based on the model.
There are no hard and fast rules regarding the proportion of residuals that should be below 0.05, if more than 50% of values are greater than 0.05 are grounds for concern (Field, 2005). In the current model 31% (n = 147) of non-redundant residuals had absolute values greater than 0.05.

6.3 Factors Extracted

The total variance explained in the PCA model is presented in Table 70. The criterion of eigenvalues greater than one indicated that up to 5 factors could be extracted explaining 52% of the total variation. The factor loadings for individual items are presented in Table 3 using promax rotation.

Table 70: National School Children Variance Explained from a Five Component PCA Model

Total Variance Explained								
Component		Initial Eigenvalues	Extraction Sums of Squared Loadings	Rotation Sums of Squared Loadings				
Total	Cronbach's Alpha	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	
1	0.868	10.034	32.367	32.367	10.034	32.367	32.367	8.069
2	0.819	2.714	8.755	41.122	2.714	8.755	41.122	6.565
3	0.76	1.322	4.266	45.388	1.322	4.266	45.388	5.205
4	0.785	1.168	3.768	49.156	1.168	3.768	49.156	5.529
5	0.526	1.024	3.302	52.458	1.024	3.302	52.458	5.076

Examination of the scree plot and Cronbach Alpha values in Table 71 for questions related to each component indicated that a three or four component solutions was more stable, explaining 49% of the total variation see Figure 25.

Figure 25: Variance Explained Scree Plot for National School Children

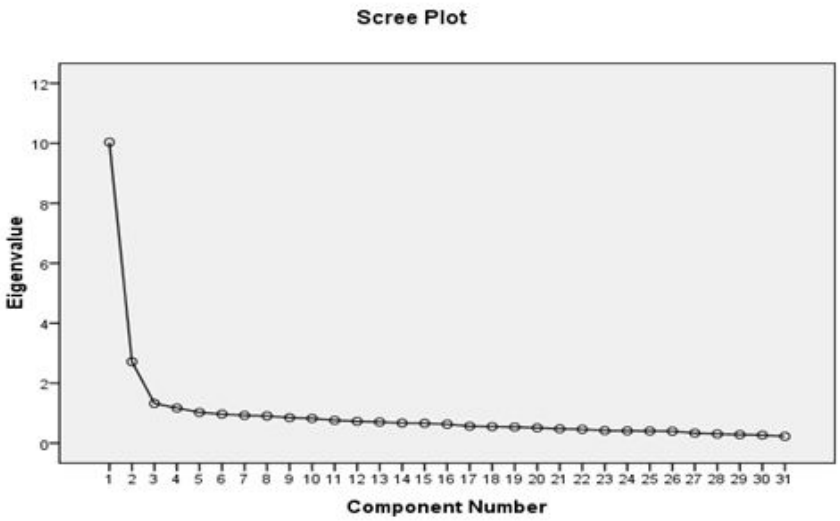


Table 71: National School Children Factor Loadings for Individual Questions

			Component			
Question	Item Description	ADI-R Domain	1	2	3	4
Q37	Response to other children's approaches	RSI	0.789	0.396	0.294	0.321
Q36	Interest in children	RSI	0.772	0.489	0.405	0.344
Q27	Social smiling	RSI	0.712	0.305	0.472	0.317
Q40	Group play	RSI	0.711	0.451	0.434	0.384
Q39	Imaginative play with peers	RSI	0.68	0.297	0.54	0.39
Q34	Imaginative social play	Communication	0.679	0.333	0.462	0.336
Q35	Imaginative play	Communication	0.633	0.235	0.487	0.226
Q38	Attention to voice	Not ADI-R	0.617	0.462	0.497	0.455
Q33	Range of facial expressions	RSI	0.566	0.269	0.513	0.197
Q31	Offering comfort	RSI	0.529	0.383	0.518	0.162
Q15	Hand and finger mannerisms	RRSB	0.39	0.759	0.295	0.28
Q14	Unusual sensory interests	RRSB	0.371	0.719	0.213	0.413
Q16	Complex body mannerisms	RRSB	0.358	0.716	0.292	0.327
Q11	Unusual preoccupations	RRSB	0.454	0.628	0.219	0.448
Q8	Compulsions & rituals	RRSB	0.459	0.593	0.163	0.565
Q10	Use of others body to communicate	RSI	0.297	0.565	0.27	0.487
Q13	Circumscribed interests	RRSB	0.501	0.549		0.381
Q18	Unusual attachment to objects	Not ADI-R	0.451	0.536	-0.113	0.353
Q20	Social chat	Communication	0.387	0.143	0.671	0.175
Q29	Offering to Share	Communication	0.501	0.44	0.654	0.229
Q30	Seeking to share enjoyment	RSI	0.55	0.429	0.649	0.109
Q26	Eye gaze	RSI	0.504	0.346	0.648	0.294
Q28	Sharing & directing attention	RSI	0.385	0.299	0.637	0.183
Q32	Quality of social overtures	RSI	0.19		0.55	
Q5	Pronoun reversal	Communication	0.287	0.21	0.194	0.745
Q3	Stereotyped utterances	Communication	0.436	0.489	0.243	0.739
Q7	Verbal rituals	RRSB	0.387	0.576	0.233	0.731
Q6	Neologisms	Communication	0.324	0.374		0.721
Q4	Inappropriate questions	Communication	0.473	0.43		0.633

6.4 Findings

The composition of children identified through the screening programme is not comparable to the clinical sample in Berument's *et al.,* (1999) validation study in which 74% of children had a diagnosis on the autism spectrum: autism 41%, atypical autism 24%, Asperger syndrome 8%. The majority of children with disabilities identified in the current study had speech and language impairments 55% followed autism spectrum disorders 14% (ASD 11%, Autistic Disorder 3%) enrolled at national schools. As a result is inappropriate to compare the findings with their validation study.

The majority of SCQ questions were developed based on the ADI-R. A four component model provided the most stable solution, explaining 49% of the total variation. The first factor explained 32% of the variation, and contained ten questions. Seven of the questions related to the Reciprocal Social Interaction (RSI) which accounts for 47% of questions based on the ADI-R (RSI) domain. Two questions were based on the Communication ADI-R domain.

The second factor explained 9% of the variation, and contained eight questions. Of these, six questions related to the Repetitive Stereotyped Patterns of Behaviour (RRSB) which accounts for 75% of questions based on this ADI-R domain, only one to the RSI domain question was in this factor.

The third and fourth factors each only explained 4% of the variation, six questions on the third and five questions on the fourth factor. Forty six percent of questions identified on both of these factors, six questions were based on the communication domain, accounting for 46% of SCQ communication based questions. Twenty seven percent of SCQ questions based on the (RSI) ADI-R domain were also represented on the third component.

7.0 Discussion

Prior to performing the principal components analysis the reliability of the SCQ (n = 39) questions were explored using Cronbach's Alpha which was unacceptably low for the sample of children identified with and without developmental disorders at and above the optimal cut off score of 12.

An acceptable Cronbach alpha was obtained for the sample of children with developmental disorders a number of questions were identified with unacceptably low correlations with the total score which were not include in the principal components analysis related to the communication domain of the ADI-R concerned current behaviour. Five questions relating to behaviour at 4-5 years of age were also excluded: Q21 Imitation, Q22 Pointing to express interest, Q23 Gestures, Q24 Nodding head to mean yes, and Q25 Shaking head to mean no.

The factor analytic findings from the SCQ validation study of Berument *et al.,* (1999) are not comparable with those from children identified with diagnosed learning disabilities (including autism spectrum disorders) identified through national schools in the current study. The majority of children in the validation study 74% had an ASD diagnosis compared with only 14% identified through screening national school children. Furthermore their study sample was composed of both children and adults. Neither are the factor analysis findings from Magyar *et al.,* (2012) relevant as the sample was composed of children with Down's syndrome with and with autism spectrum disorders.

In the current sample of children with diagnosed developmental disorders a four factor solution explained 49% of the total variation. Most of the variation was explained in the first and second components. Forty seven percent of SCQ questions developed based on the ADI-R Reciprocal Social Interaction (RSI) domain were represented on the first component, and 75% of questions in the second component were based on the Reciprocal Repetitive Stereotyped Behaviour (RRSB) domain. Forty six percent of questions based on the ADI-R Communication domain were included in the PCA model represented in the third and fourth factors each of which only explained 4% of the total variation. However the same percentages of questions in the communication domain were excluded from the PCA model as they correlated poorly with the total score. An additional 27% of ADI-R questions based on the RSI domain were represented on the third component.

In conclusion the main findings from performing this factor analysis is that a substantial number of communication items did not correlate well with the total score among a general school going population of children identified with diagnosed developmental disabilities including autism spectrum disorders these items need to be revised for using the screen in a general population setting.

Although the discriminative ability of the SCQ performed well at differentiating autism from children with and without developmental disorders at the optimal cut off score of 12 and over individual SCQ questions correlated poorly with the total score for children identified in this score range.

CHAPTER 12
DISCUSSION

1.0 The EAIS Study

Research methods to examine autism prevalence rates have varied greatly across Europe making interpretation and harmonisation of results difficult. What is required is a harmonised methodology to collect prevalence rates across Europe. This was the goal of the European Autism Information System (EAIS) project (Posada and Ramirez 2008). The project reported here is the first study in Europe to implement and apply the EAIS protocol. In this discussion chapter we will discuss the main outcomes from the study and draw some conclusions about the feasibility of its application, firstly in Ireland, and then across Europe. The potential value to the field of autism epidemiology of the EAIS methodology will be considered. The key features of the EAIS study were the decision to develop a standardized protocol to study children in primary schools, in a restricted age range (6 to 11), and the decision to use a multi-stage screening approach.

Children were screened with the Social Communication Questionnaire (SCQ: Rutter et al., 2003). This is a 40 item question parental report questionnaire that asks about characteristic autistic behaviour. It was developed based on items from the Autism Diagnostic Interview – Revised (ADI-R: Lord *et al.,* 1994) (specifically the Communication (32%) Reciprocal Social Interaction (37%) and Restricted Repetitive Stereotyped Behaviour (20%) domains) and has established validity for a diagnosis of autism (Berument *et al.,* 1999). Almost half of the SCQ questions are related to the children's development and behaviour at 4-5 years of age. The recommended cut off score for autism spectrum disorder is ($\geq$ 15). The SCQ has previously only been validated for use among clinical samples of school aged children with ASDs and other developmental disorders (Berument *et al.,* 1999; Charman *et al.,* Chandler *et al.,* 2007; Corsello *et al.,* 2007). In the validation study by Berument *et al.,* (1999) both adults and children were included in the clinical samples. This study is the first large scale study to examine its performance in a national school based setting.

2.0 Study Phases

The core of this study is a large survey (n=7,951) of children attending national (i.e. primary) schools and special schools in 3 regions of Ireland, namely Cork, Galway, and Waterford. The study was done in 3 phases:

- In the first phase, parents of children in national school were sent a study booklet which included the SCQ.

- In the second phase a repeat SCQ was obtained from parents of all children who had obtained high (15 or more) and moderate (12 to 14) scores on the first SCQ, as well as a random sample of those who had obtained normal scores.

- In the third phase clinical records were abstracted to confirm clinical diagnoses for those children with parent-reported diagnosed disorders who had moderate and high scores. The aim of this phase was to validate parent reported diagnoses, as recorded in the study booklet, and to identify those with a pre-existing diagnosis and those who didn't. Those children with high scores who had neither a pre-existing diagnosis nor a psychological assessment are being referred for multi-disciplinary assessment (this is outside the scope of the Ph.D. study).

Relatively few epidemiological studies of autism have been done in a primary school setting. The Childhood Autism Screening Test (CAST: Scott *et al.,* 2002) was validated among a sample of school aged children ranging in age from 4 to 11 years. However, the validation studies for the CAST were hampered by relatively poor response rates of between 17% and 26%, from parents selected to complete the instrument (Scott *et al.,* 2002; Allison *et al.,* 2007; Williams *et al.,* 2005; 2008).

The Autism Spectrum Screening Questionnaire (ASSQ: Ehlers & Gillberg, 1993) was also validated among samples of school aged children. This earlier study, which in many ways resembles ours, was done by Posserud *et al.*, (2009) who screened 9,430 children aged from 7-9 years. These children were identified through the Norwegian Bergen Child Longitudinal Study (2002).

Seventy percent of parents provided informed consent for their child to participate. Both parents and teachers completed the ASSQ. Children who had high scores were invited for further clinical assessment, along with a large group of screen negative children. The authors reported that the ASSQ was well suited as a general population screen, combining the parent and teacher ASSQ scores, and using a cut-off score of ($\geq$17) that provided the most efficient screen with sensitivity of 0.91 and specificity of 0.86.

The validation sample in the Norwegian study was not a perfectly representative of the general population, as it included more children with high ASSQ scores and other mental health problems than would be expected (Posserud *et al.,* 2009. One of the major challenges of this specific piece of research was the large resources required. Forty national schools and twelve special schools took part in the research giving a total of almost 240 different classes and teachers. Interpersonal relationship building between research staff and school staff (teachers, principal's administration and resource staff) was essential to achieving high response rates. Teachers were crucial in reminding parents via children to return the questionnaires.

So far we have presented a review of the literature in (Chapter 1). Chapter 2 is a detailed exposition for the methods used in this study. In chapter 3 we present the demographics of our study population, and the response rates from the national school data. In chapter 4 we present the results of the SCQ scores for the national school children.

In chapter 5 we present the demographics, the response rates, and the SCQ scores for the children in the special education schools. In chapter 6 we present an analysis of discriminative validity for the national school children. Chapter 7 presents this for the special education school children. In chapter 8 we present a factor analysis for the national school children who had parent reported diagnoses. In chapter 9 we present test re-test reliability for both sets of children. In chapter 10 we present a comparison of SCQ scores with previous psychological assessments, or ASD diagnoses. In this discussion we will not repeat material already presented elsewhere.

3.0 Fieldwork Issues

The overall response rate, in the national school sample, was high at 70%. Although a representative sample of children were screened at disadvantaged national schools, the response rate of 30% from parents of these children was poor. The majority of returns were completed by parents for boys. Literacy and language issues were possible factors contributing to the poor response rates at disadvantaged schools. Poor response rates, only 36%, were obtained at special education schools, as fieldworkers did not have the opportunity to liaise with teachers who taught children on a one to one basis and could not be interrupted during the school day.

The majority of study booklets were completed by primary caregivers who reported they provided most care for the study child since birth 98%. Study Booklets which included the SCQ were completed by 86% of study children's mothers. On this basis we anticipated that information provided relating to the study child's development would be accurately reported. There were insufficient resources to perform all three phases within the defined period when fieldwork was undertaken September 2010 to June 2011. 1st phase parent completed study booklets, 2nd recompletion of SCQ for high to moderate scores, 3rd verification of parent reported diagnosis.

As a result each phase of the study was performed separately; the 3rd phase verifying parent reported diagnosis was completed in November 2012. As a consequence of the time period between study phases we were unable to contact a number of children's parents who had changed their contact numbers, moved address or left the country in the cases of parents of non-Irish children. Performing the three study phases within the defined fieldwork period was also important to keep to a minimum the number of parents we were unable to contact at follow up.

An essential component for future studies is the employment of sufficient fieldworkers to work in the schools to liaise with teachers to maintain high response rates, manually calculate SCQ scores as study booklets are returned to teachers by parents to identify children with moderate and high scores quickly. Fieldworkers can then contact the parents of these children, both to secure access to psychological assessments, and to re-administer the SCQ.

Children who require referrals for ADOS / ADI-R assessment can then be identified within a relatively short time period, perhaps. 2 to 3 months from when fieldwork commenced at the school.

4.0 SCQ Results

Apart the studies by Mulligan *et al.,* (2009) and Chandler *et al.,* (2007) the SCQ has not been used previously to screen children within a national school setting. The distribution of scores was similar to the findings reported in these studies. The majority of children scores were in the normal range (0-11) 92%, with 4% scoring in the moderate and high 4% score ranges. Mean scores for males were significantly higher than for females. Younger children had higher scores than older children. One explanation for these findings is the fact that almost ½ of the questions related to the child's behaviour at 4-5 years of age which may have been difficult to answer for parents of older children.

Scores for children enrolled at disadvantaged schools were higher than for mainstream school children. It was observed that children whose mothers were only educated to primary or secondary level, or working in skilled and semi-skilled manual occupations, had mean scores were higher than those for children whose mothers were in more advantaged socio-economic groups. These findings indicate that the mothers of these children either had greater difficulty completing the SCQ or these study children had greater degrees of impairment as measured by the screener.

At special education schools the majority of children obtained high ($\geq$15) SCQ scores. Although mean scores were highest for children with a diagnosis of autism spectrum disorder scores, were also high for children with genetic disorders e.g. Down's syndrome, Cerebral Palsy. As a consequence of the poor response rate from parent's a biased sample of returns was obtained, that was not representative of children attending these schools.

5.0 Response Rates

The fieldwork protocol was inappropriate for the special education school population. High response rates from parents were feasible at mainstream schools as fieldworks had the opportunity to liaise with teachers and school staff. The primary focus should have been on obtaining completion of a written consent form (only and not the study booklet) requesting permission to abstract psychological and multidisciplinary assessments from parents of all eligible children 6-11 years of age with and without a diagnosis of autism spectrum disorder. One would expect this approach would have resulted in better response rates from parents. The problems regarding the low response rates at disadvantaged schools are more difficult to resolve. I was informed by a number of school principals that literacy issues were the primary reason for the poor response rates. Resources would have been required to assist parent complete the study booklet on a one to one basis. The support of home school liaison officers at these schools followed up eligible children who they expected to have undiagnosed learning and behavioural difficulties.

6.0 Consent Issues

Clinicians at some services stated the consent form did not specifically address the clinical data which we wanted to abstract from children's records. A separate consent form was sent to the parents of children from these services specifically stating the clinical data we wanted to abstract from psychological assessments e.g. summary scores for recent cognitive, speech and language, adaptive functioning assessments, and results of ADOS/ADI-R if performed as part of the evaluation process. An important component for future studies is to liaise with child and adolescent mental health services in study regions to ensure they agree with the format of consent form to access records and agree with service specific requirements they impose for requesting parental consent to access children's psychological and multidisciplinary assessments.

7.0 The SCQ as a Screening Instrument

This study shows, that for primary school age children, that a cut off score below the usually recommended cut off point was required to optimise sensitivity and specificity for the identification of children with a diagnosis of autism spectrum disorder from children with and without other developmental disorders at national schools. While this optimum cut-off leads to good sensitivity (0.91) and specificity (0.92), the positive predictive value is low at 12%, indicating that most of the positive test results are likely to be false positives.
This means that the majority of positive test children referred for expensive and resource consuming ADOS / ADI-R evaluations would not be diagnosed with an ASD. The main strength of the SCQ is the good negative predictive value at 99%, so that children who screened negative are unlikely to have an ASD diagnosis. The SCQ was a slightly better screening instrument for males, providing a sensitivity of 0.98 and specificity 0.91, than for females, where the sensitivity was 0.87 and the specificity 0.95. Establishing optimal cut off scores for children on the basis of age proved to be more difficult, as that children in different age groups had different optimal cut off points. A cut off as low as ($\geq$9) was optimal for children 10-11 years of age and as high as ($\geq$16) for children 8-9 years of age. The screen was less effective for identifying older children whose mean scores were lower indicating lower degrees of impairment as measured by the SCQ. These findings indicate the SCQ may not be an appropriate screener for higher functioning older school children.

Looking only at those children whose parents had reported a developmental problem, the optimal cut off score ($\geq$13) provided a sensitivity of 0.90 and specificity of 0.81 for differentiating ASDs from other developmental disorders. A higher positive predictive value of 43% was obtained, as expected, since the screen was originally developed for use within a clinical setting. The negative predictive value remained high at 98%.

The optimal for males ($\geq$12) (sensitivity 0.90 specificity 0.82) was slightly lower than that for females ($\geq$14) (sensitivity 0.92 specificity 0.82). Although children in the 8-9 age group required a higher cut off to achieve optimal sensitivity and specificity ($\geq$16) compared to the younger 6-7 age group and older 10-11 age group ($\geq$14).

The SCQ would seem to have better discriminative validity for differentiating between diagnostic groups, which is how it was intended to be used in clinical settings, as opposed to the identification of children with ASDs from amongst those with and without developmental difficulties which is how a screen would be used in an epidemiological setting. This is, of course, predictable. The SCQ proved to be an effective screening instrument for use in a national school setting, providing high sensitivity and specificity, at a cut off score below that recommended in the validation study by Berument *et al.,* (1999) of (≥12) for the identification of children with a diagnosis on the autism spectrum from those with and without other developmental disorders.

A cut off point of (≥13) provided optimal sensitivity and specificity for the identification of children with ASDs from those with other developmental disorders. Positive predictive values were very low, at 14%, when the screen was used for the identification of children with a diagnosis on the autism spectrum from children with and without developmental disorders, but higher, at 42% when used for differentiating ASDs from other developmental disorders.

The main strength of the SCQ was the high negative predictive values that ranged from 98% to 99% for the identification of children with ASDs from those with and without other developmental disorders. This means that children who score negative are very unlikely to be at risk of having an ASD so resources can be focused on following up all screen positive children. Overall the SCQ is a useful, though expensive, screening tool for epidemiological purposes, but it would benefit from further development, and it might be worthwhile to develop a specific screening instrument for population prevalence studies, building on the ADI-R.

We observed greater sensitivity and specificity using the SCQ both for the identification of children with an ASD diagnosis from children with and without developmental disorders in comparison to previous clinical based studies by Charman *et al.,* 2007; Corsello *et al.,* 2007; and Chandler *et al.,* 2007. However positive predictive value in the current study was considerably lower 12% and 43% for the identification of children with ASD from children with/out developmental disorders, and from children with other developmental disorders. These studies include samples of children with both high and low IQ profiles.

In the present study we had insufficient resources to abstract clinical data for all children with parent reported diagnosed developmental disorders. We attempted to collate clinical data for children with a confirmed diagnosis of autism spectrum disorder e.g. cognitive, speech and language, adaptive behaviour assessment. The results of ADOS / ADI-R were also abstracted when performed as part of the assessment process. There was insufficient clinical data abstracted that provided a good profile of the functioning of these children. In the current study children were screened in a relatively restricted age range 6-11 yrs. We specifically chose those screen children in this age range to screen all national school children enrolled in 1st to 6th class, although a proportion in both the lowest and highest class were not eligible to take part.

Chandler *et al.,* (2007) and Charman *et al.,* (2007) also screened children in restrictive age range. Charman *et al.,* (2007) highlighted a number of factors that influence the performance of a screening instrument in different populations (clinical and epidemiological) in addition to the prevalence of autism spectrum disorders. The child's characteristics (clinical diagnosis, IQ, age) of those with and without the disorder, family factors (parental education, knowledge about autism) and methodological factors, and whether the screen was completed before or after assessment, will all affect how the screening instrument performs.

8.0 Evaluation of the EPAP Screening Protocol

The main strengths of the current study were the age range chosen which allowed us to screen the majority of national school children from 1st to 6th class. The majority of children across the EU attending primary (national) schools are in the 6-11 year age range. Overall response rates were high at national schools, a multistage screening approach was implemented, and the majority of children identified with a parent reported ASD diagnosis had that diagnosis validated from psychological and multi-disciplinary assessments. The SCQ was validated as an effective screening instrument for use in a national school setting.

Study weaknesses included poor response rates at disadvantaged and special education schools. Significantly greater resources would have been required to enhance response rates at disadvantaged schools as literacy issues were potentially one of the main reason for the poor response rates.

Following most children at potential risk of an ASD (high/moderate scores) would entail home school liaison officers and fieldworkers completing study booklets on a one to one basis with parents. Due to resource limitations each screening phase was performed separately, which prolonged the duration of the screening process.

The SCQ test retest reliability would probably have been higher if this phase of the study had been completed within 3 months of the initial completion of the SCQ by the parents, and it would have better reflected the children's difficulties when screening commenced. There were insufficient resources to validate all of the parent reported diagnosis reported in study booklets.

Although sensitivity and specificity of the SCQ were both high, the positive predictive value was low, so a large proportion of children identified with high scores would not had an ASD diagnosis after ADOS/ADI-R assessments. The main strength of the SCQ was the high negative predictive value, if a child did not score positive they were very unlikely to be at risk of an ASD.

9.0 Recommendations for Public Health Policy & Practice

The process of screening and diagnosing autism spectrum disorders is complex requiring input from multiple social, educations, medical and psychological services. Taking these factors into consideration the following recommendations are suggested for future research within the context of the present study:

- Determine if there is a trend for increased or decreased prevalence rates over time in the study regions when screening was performed. Children should be rescreened in these regions in five years' time using the same study methodology.
- Given the current economic climate it is essential to undertaken studies to determine the financial burden of autism spectrum disorders among families taking direct and indirect cost into consideration, including education and medical cost to estimate saving to society of early diagnosis and intervention of autism spectrum disorders.

- Having successfully screened children using the EPAP protocol in Ireland it is now imperative to explore the feasibility of implementing the protocol in other countries in the EU undertaking a second phase of pilot studies in defined study regions.
- Having validated parent reported diagnosis of ASDs it was evident that there was variation in the assessment processes used by different psychological services for diagnosing children with ASDs. There is a requirement for the HSE to develop and implement a standardised protocol for Child and Adolescent Mental Health (CAMHS) services for the diagnosis of these disorders based as established criteria for example following the National Institute for Health & Care Excellence (NICE, 2011) guidelines implemented in the UK.
- An epidemiological database should be established by the HSE for all children who have received a diagnosis of autism spectrum disorder through CAMHS services which will be beneficial for future Irish epidemiological studies.

Screening is an essential component of an autism prevalence protocol which must be executed correctly prior to moving onto the assessment stages of the study protocol. We are currently in the process of contacting the parents of children identified who required further assessment. The outcomes of this final phase of the study will determine the effectives of a model for use in other EU countries in order to evaluate:

- The willingness of the parents to consent to the assessment process for "at risk" children identified.
- The financial resources required to evaluate these children, and the time line to complete the process.
- The characteristics of children referred for assessment diagnosed on the autism spectrum for example previously reported parental concerns, the child's developmental and medical history, difficulties reported by teachers, points of contact with the health care system from birth, parental socio-economic characteristics, ethnicity and outcome of the evaluations.

- As autism is a lifelong disorder the availability of on-going behaviour and medical, educational interventions and social services in the study regions are essential to support children identified and diagnosed on the autism spectrum. These services should be provided within the study regions

However the availability of autism specific services will vary considerably for countries willing to participate in the study within the EU. An important component of future research is to evaluate the availability of services for children in different countries in the EU with specific emphasis on referral patterns for preschool and school aged children.

10.0 Overall Conclusion

This study has demonstrated the feasibility of the EPAP protocol for screening national (primary) school children using the SCQ as a primary screening instrument. In additional to the recommendations outlined for future research it is essential that all screening phase of this protocol are performed simultaneously in future studies across the EU to ensure the identification of moderate and high score children as quickly as possible, obtain reliable re-test reliability data for moderate and high scoring children, and access to multidisciplinary and psychological assessments, minimising the number of parents who cannot be followed up. Completion of all screening phases within a 2-3 month period from the commencement of fieldwork will ensure that children is probably desirable, although it has significant implications for the resources that would be required to carry out these studies.

REFERENCES

Adkins, P. G., & Aissa, T. A. (1979). The misdiagnosis of Matthew. *Academic Therapy, 14*, 335 – 339.

Aiken, L. R. (1985). Three Coefficients for Analyzing the Reliability, and Validity of Ratings. *Educational and Psychological Measurement, 45*, 131-142.

Akshoomoff, N., Corsello, C., & Schmidt, H. (2006). The Role of the Autism Diagnostic Observation Schedule in the Assessment of Autism Spectrum Disorders in School and Community Settings. *The California School Psychologist, 11*, 7-19.

Aldridge, F. J., Gibbs, V. M., Schmidhofer, K., & Williams, M. (2012). Investigating the clinical usefulness of the Social Responsiveness Scale (SRS) in a tertiary level, autism spectrum disorder specific assessment clinic. *Journal of Autism and Developmental Disorders, 42*(2), 294-300.

Algozzine, B., & Ysseldyke, J. E. (1986). The future of the LD field: screening and diagnosis. *Journal of Learning Disabilities, 19*(7), 394-398.

Allen, C. W., Silove, N., Williams, K., & Hutchins, P. (2007). Validity of the social communication questionnaire in assessing risk of autism in preschool children with developmental problems. *Journal of Autism and Developmental Disorders, 37*(7), 1272-1278.

Allison, C., Williams, J., Scott, F., Stott, C., Bolton, P., Baron-Cohen, S., & Brayne, C. (2007). The Childhood Asperger Syndrome Test (CAST): test-retest reliability in a high scoring sample. *Autism, 11*(2), 173-185.

American Education Research Association. (1999). National Council on Measurement in Education, Standards for Education and Psychological Testing Washington D.C: AERA.

American Psychological Association, A. (1966). S*tandards for Educational and Psychological Tests and Manuals*. Washington DC. American. Psychological Association.

American Psychological Association. (1987). *Diagnostic and Statistical Manual of Mental Disorders* (3rd (edition revised) ed.). Washington DC. American Psychiatric Association.

American Psychological Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.). Washington D.C.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev).

Amiet, C., Gourfinkel-An, I., Bouzamondo, A., Tordjman, S., Baulac, M., Lechat, P., . . . Cohen, D. (2008). Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis. *Biological Psychiatry, 64*(7).

Ashwood, P., Anthony, A., Pellicer, A. A., Torrente, F., Walker-Smith, J. A., & Wakefield, A. J. (2003). Intestinal lymphocyte populations in children with regressive autism: evidence for extensive mucosal immunopathology. *Journal of Clinical Immunology, 23*(6), 504-517.

Asperger, H. (1944). Die autistischen Psyhopathen im Kindeslter. *Arch Psychiar Nervenkrankh 117* 76-136.

Association, Speech & Language Hearing Association (1991). Guidelines for the audio logic assessment of children from birth through 36 months of age. *ASHA Supplement* (5), 37-43.

Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., & Drew, A. (2000). A screening instrument for autism at 18 months of age: a 6-year follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*(6), 694-702.

Baird, G., Charman, T., Cox, A., Baron-Cohen, S., Swettenham, J., Wheelwright, S., & Drew, A. (2001). Screening and surveillance for autism and pervasive developmental disorders. *Archives of Disease in Childhood, 84*(6), 468-475.

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet, 368*(9531), 210-215.

Banks J., S, Mc Coy. (2011). National Council for Special Education - A Study of the Prevalence of Special Education Needs. Economic & Social Research Institute (ESRI).

Baranek, G. T., Foster, L. G., & Berkson, G. (1997). Tactile defensiveness and stereotyped behaviours. *The American Journal of Occupational Therapy, 51*(2), 91-95.

Barbaro, J., & Dissanayake, C. (2009). Autism spectrum disorders in infancy and toddlerhood: a review of the evidence on early signs, early identification tools, and early diagnosis. *Journal of Development and Behavioural Paediatrics 30*(5), 447-459.

Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *The British Journal of Psychiatry 161*, 839-843.

Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry, 194*(6), 500-509.

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*(1), 5-17.

Bauman, M. L. (2010). Medical co morbidities in autism: challenges to diagnosis and treatment. *Neurotherapeutics, 7*(3), 320-327.

Beglinger, L. J., & Smith, T. H. (2001). A review of sub typing in autism and proposed dimensional classification model. *Journal of Autism and Developmental Disorders, 31*(4), 411-422.

Bennett, K. J., Lipman, E. L., Brown, S., Racine, Y., Boyle, M. H., & Offord, D. R. (1999). Predicting conduct problems: can high-risk children be identified in kindergarten and grade 1? *Journal of Consulting and Clinical Psychology, 67*(4), 470-480.

Bennett, T., Szatmari, P., Bryson, S., Volden, J., Zwaigenbaum, L., Vaccarella, L., . . . Boyle, M. (2008). Differentiating autism and Asperger syndrome on the basis of language delay or impairment. *Journal of Autism and Developmental Disorders, 38*(4), 616-625.

Bertrand, J., Mars, A., Boyle, C., Bove, F., Yeargin-Allsopp, M., & Decoufle, P. (2001). Prevalence of autism in a United States population: the Brick Township, New Jersey, investigation. *Paediatrics, 108*(5), 1155-1161.

Berument, S. K., Rutter, M., Lord, C., Pickles, A., & Bailey, A. (1999). Autism screening questionnaire: diagnostic validity. *The British Journal of Psychiatry, 175*, 444-451.

Bishop, D. V., & Norbury, C. F. (2002). Exploring the borderlands of autistic disorder and specific language impairment: a study using standardised diagnostic instruments. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 43*(7), 917-929.

Bishop, D. V. M. (1998). Development of the Children's Communication Checklist (CCC) . A method for assessing qualitative aspects of communicative impairment in children. *Journal of Child Psychology and Psychiatry, 39* 879-891.

Bland, J. M., & Altman, D. G. (1997). Statistics notes: Cronbach's alpha. *British Medical Journal, 314,* 572.

Bolte, S., Holtmann, M., & Poustka, F. (2008). The Social Communication Questionnaire (SCQ) as a screener for autism spectrum disorders: additional evidence and cross-cultural validity. *Journal of the American Academy of Child and Adolescent Psychiatry 47*(6), 719-720.

Bolte, S., & Poustka, F. (2002). The relation between general cognitive level and adaptive behaviour domains in individuals with autism with and without co-morbid mental retardation. *Child Psychiatry and Human Development, 33*(2), 165-172.

Bolte, S., & Poustka, F. (2004). Diagnostic Observation Scale for Autistic Disorders: initial results of reliability and validity. *Z Kinder Jugendpsychiatr Psychother, 32*(1), 45-50.

Bolton, P., Macdonald, H., Pickles, A., Rios, P., Goode, S., Crowson, M., . . . Rutter, M. (1994). A case-control family history study of autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 35*(5), 877-900.

Bordignon, C., & Lam, C. M. (2004). The early assessment conundrum: Lessons from the past, implications for the future. *Psychology in the Schools, 41* (7), 737-749.

Boucher, J., Lewis, V., & Collis, G. M. (2000). Voice processing abilities in children with autism, children with specific language impairments, and young typically developing children. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 41*(7), 847-857.

Bowman, E. P. (1988). Asperger's syndrome and autism: the case for a connection. *The British Journal of Psychiatry, 152*, 377-382.

Brace, N., Kemp, R., & Snelgar, R. (2006). *SPSS for Psychologists: A Guide to Data Analysis using SPSS for Windows*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Brinks, P. J., & Wood, M. J. (1998). *Advances design in nursing research.* . CA: Sage Thousand Oaks.

Brown, J., & Prelock, P. A. (1995). Brief report: the impact of regression on language development in autism. *Journal of Autism and Developmental Disorders, 25*(3), 305-309.

Bryson, S. E., Zwaigenbaum, L., Brian, J., Roberts, W., Szatmari, P., Rombough, V., & McDermott, C. (2007). A prospective case series of high-risk infants who developed autism. *Journal of Autism and Developmental Disorders, 37*(1), 12-24.

Buie, T., Campbell, D. B., Fuchs, G. J., 3rd, Furuta, G. T., Levy, J., Vandewater, J., . . . Winter, H. (2010). Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Paediatrics, 125 Suppl 1*, S1-18.

Buitelaar, J. K., Van der Gaag, R., Klin, A., & Volkmar, F. (1999). Exploring the boundaries of pervasive developmental disorder not otherwise specified: analyses of data from the DSM-IV Autistic Disorder Field Trial. *Journal of Autism and Developmental Disorders, 29*(1), 33-43.

Burack, J. A., Iarocci, G., Bowler, D., & Mottron, L. (2002). Benefits and pitfalls in the merging of disciplines: the example of developmental psychopathology and the study of persons with autism. *Development and Psychopathology, 14*(2), 225-237.

Burd, L., Ivey, M., Barth, A., & Kerbeshian, J. (1998). Two males with childhood disintegrative disorder: a prospective 14-year outcome study. *Developmental Medicine and Child Neurology, 40*(10), 702-707.

Campbell, M., & Shay, J. (1995). Pervasive Developmental Disorders In H. I. Kaplan & B. J. Sadock (Eds.), *Comprehensive Text book of Psychiatry IV* (pp. 2277-2293). Baltimore, MD: Williams & Wilkins.

Carr, E. G., & Owen-Deschryver, J. S. (2007). Physical illness, pain, and problem behavior in minimally verbal people with developmental disabilities. *Journal of Autism and Developmental Disorders, 37*(3), 413-424.

Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2008). Asperger syndrome and autism: a comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders, 38*(1), 72-85.

Challman, T. D., Barbaresi, W. J., Katusic, S. K., & Weaver, A. (2003). The yield of the medical evaluation of children with pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 33*(2), 187-192.

Chandler, S., Charman, T., Baird, G., Simonoff, E., Loucas, T., Meldrum, D., . . . Pickles, A. (2007). Validation of the social communication questionnaire in a population cohort of children with autism spectrum disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(10), 1324-1332.

Charman, T., & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 43*(3), 289-305.

Charman, T., Baird, G., Simonoff, E., Loucas, T., Chandler, S., Meldrum, D., & Pickles, A. (2007). Efficacy of three screening instruments in the identification of autistic-spectrum disorders. *The British Journal of Psychiatry, 191*, 554-559.

Charman, T., Taylor, E., Drew, A., Cockerill, H., Brown, J. A., & Baird, G. (2005). Outcome at 7 years of children diagnosed with autism at age 2: predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 46*(5), 500-513.

Chawarska, K., Klin, A., Paul, R., & Volkmar, F. (2007). Autism spectrum disorder in the second year: stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry, and Allied Disciplines 48*(2), 128-138.

Clark, A., & Harrington, R. (1999). On diagnosing rare disorders rarely: appropriate use of screening instruments. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 40*(2), 287-290.

Cody, H., Pelphrey, K., & Piven, J. (2002). Structural and functional magnetic resonance imaging of autism. *International Journal of Developmental Neuroscience, 20*(3-5), 421-438.

Constantino, J. N. (2011). The quantitative nature of autistic social impairment. *Paediatric Research, 69*(5 Pt 2), 55R-62R.

Constantino, J. N., Abbacchi, A. M., Lavesser, P. D., Reed, H., Givens, L., Chiang, L., . . . Todd, R. D. (2009). Developmental course of autistic social impairment in males. *Development and Psychopathology, 21*(1), 127-138.

Constantino, J. N., Davis, S. A., Todd, R. D., Schindler, M. K., Gross, M. M., Brophy, S. L., . . . Reich, W. (2003). Validation of a brief quantitative measure of autistic traits: comparison of the social responsiveness scale with the autism diagnostic interview-revised. *Journal of Autism and Developmental Disorders, 33*(4), 427-433.

Constantino, J. N., & Gruber, C. P. (2005). Social Responsiveness Scale. Los Angeles Western Psychological Services.

Constantino, J. N., Gruber, C. P., Davis, S., Hayes, S., Passanante, N., & Przybeck, T. (2004). The factor structure of autistic traits. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 45*(4), 719-726.

Constantino, J. N., Hudziak, J. J., & Todd, R. D. (2003). Deficits in reciprocal social behavior in male twins: evidence for a genetically independent domain of psychopathology. *Journal of the American Academy of Child and Adolescent Psychiatry, 42*(4), 458-467.

Constantino, J. N., Lajonchere, C., Lutz, M., Gray, T., Abbacchi, A., McKenna, K., . . . Todd, R. D. (2006). Autistic social impairment in the siblings of children with pervasive developmental disorders. *The American Journal of Psychiatry, 163*(2), 294-296.

Constantino, J. N., Lavesser, P. D., Zhang, Y., Abbacchi, A. M., Gray, T., & Todd, R. D. (2007). Rapid quantitative assessment of autistic social impairment by classroom teachers. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(12), 1668-1676.

Constantino, J. N., Przybeck, T., Friesen, D., & Todd, R. D. (2000). Reciprocal social behaviour in children with and without pervasive developmental disorders. *Journal of Development and Behavioural Paediatrics, 21*(1), 2-11.

Constantino, J. N., & Todd, R. D. (2000). Genetic structure of reciprocal social behaviour. *The American Journal of Psychiatry, 157*(12), 2043-2045.

Constantino, J. N., & Todd, R. D. (2003). Autistic traits in the general population: a twin study. *Archives of General Psychiatry, 60*(5), 524-530.

Constantino, J. N., & Todd, R. D. (2005). Intergenerational transmission of sub threshold autistic traits in the general population. *Biological Psychiatry, 57*(6), 655-660.

Conti-Ramsden, G., Simkin, Z., & Botting, N. (2006). The prevalence of autistic spectrum disorders in adolescents with a history of specific language impairment (SLI). *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 47*(6), 621-628.

Cook, D. A., & Beckman, T. J. (2006). Current concepts in validity and reliability for psychometric instruments: theory and application. *The American Journal of Medicine 119*(2), e167-116.

Cook, E. H., Jr., Lindgren, V., Leventhal, B. L., Courchesne, R., Lincoln, A., Shulman, C., . . . Courchesne, E. (1997). Autism or atypical autism in maternally but not paternally derived proximal 15q duplication. *American Journal of Human Genetics, 60*(4), 928-934.

Corbett, J., & Harris, R. (1977). Progressive disintegrative psychosis of childhood. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 18*(3), 211-219.

Corsello, C., Cook, E., & Leventhal, M. (2003, *April).* A screening instrument for autistic spectrum disorders . *Paper presented at the Society for Research in Child Development Biennial Conference,* Tampa, FL.

Corsello, C., Hus, V., Pickles, A., Risi, S., Cook, E. H., Jr., Leventhal, B. L., & Lord, C. (2007). Between a ROC and a hard place: decision making and making decisions about using the SCQ. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 48*(9), 932-940. Council, M. R. (2001). MRC Review of Autism Research. London.

Cox, A., Klein, K., Charman, T., Baird, G., Baron-Cohen, S., Swettenham, J., . . . Wheelwright, S. (1999). Autism spectrum disorders at 20 and 42 months of age: stability of clinical and ADI-R diagnosis. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 40*(5), 719-732.

Cronbach, L. J., & Meehl, P. E. (1955). Construct validity in psychological tests. *Psychological Bulletin, 52*(4), 281-302.

Cubala-Kucharska, M. (2010). The review of most frequently occurring medical disorders related to aetiology of autism and the methods of treatment. *Acta Neurobiologiae Experimentalis, 70*(2), 141-146.

Cuccaro, M. L., Shao, Y., Grubber, J., Slifer, M., Wolpert, C. M., Donnelly, S. L., . . . Pericak-Vance, M. A. (2003). Factor analysis of restricted and repetitive behaviors in autism using the Autism Diagnostic Interview-R. *Child Psychiatry and Human Development, 34*(1), 3-17.

Daniels, A. M., Rosenberg, R. E., Law, J. K., Lord, C., Kaufmann, W. E., & Law, P. A. (2011). Stability of initial autism spectrum disorder diagnoses in community settings. *Journal of Autism and Developmental Disorders, 41*(1), 110-121.

Davidovitch, M., Glick, L., Holtzman, G., Tirosh, E., & Safir, M. P. (2000). Developmental regression in autism: maternal perception. *Journal of Autism and Developmental Disorders, 30*(2), 113-119.

De Bildt, A., Sytema, S., Ketelaars, C., Kraijer, D., Mulder, E., Volkmar, F., & Minderaa, R. (2004). Interrelationship between Autism Diagnostic Observation Schedule-Generic (ADOS-G), Autism Diagnostic Interview-Revised (ADI-R), and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) classification in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders, 34*(2), 129-137.

De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child & Adolescent Psychiatry, 7*(3), 131-136.

DeNeef, P., & Kent, D. L. (1993). Using treatment-trade-off preferences to select diagnostic strategies: linking the ROC curve to threshold analysis. *International Journal for Medical Decision Making, 13*(2), 126-132.

Deorgatis, L. R., & Lynn, L. L. (1998). Psychological tests in screening for psychiatric disorder. In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes.* (2nd ed., pp. 41-79). New York Erlbaum.

DeVellis, R. F. (2003). *Scale development: Theory and applications* (2nd ed.). CA, Newbury Park Sage Publications.

DeVon, H. A., Block, M. E., Moyle-Wright, P., Ernst, D. M., Hayden, S. J., Lazzara, D. J., . . . Kostas-Polston, E. (2007). A psychometric toolbox for testing validity and reliability. *Journal of Nursing Scholarship, 39*(2), 155-164.

Department of Education & Science. (2003). *The Report of the Task Force on Autism, Education Provision and Support for Persons with Autism Spectrum Disorders.*

Disabilities Act (2005) Act No 14 of 2005.

Downing, S. M., & Haladyna, T. M. (2004). Validity threats: overcoming interference with proposed interpretations of assessment data. *Medical Education, 38*(3), 327-333.

Dunn, L. M. (1981). Peabody Picture Vocabulary Test Revised. Circle Pines (MN): American Guidance Service.

Dunn, L. M., Whetton, C., & Burley, J. (1997). British Picture Vocabulary Scale (2nd ed.). NFER-Nelson.

Dutton, D. B. (1979). Patterns of ambulatory health care in five different delivery systems. *Medical Care 17*(3), 221-243.

Duvall, J. A., Lu, A., Cantor, R. M., Todd, R. D., Constantino, J. N., & Geschwind, D. H. (2007). A quantitative trait locus analysis of social responsiveness in multiplex autism families. *The American Journal of Psychiatry, 164*(4), 656-662.

Dworkin, P. H., & Glascoe, F. P. (1997). Early intervention of developmental delays: How do you measure up? *Contemporary Paediatrics, 14*, 158-168.

Dwyer, A. J. (1996). In pursuit of a piece of the ROC. *Radiology, 201*(3), 621-625.

Dykens, E., & Volkmar, F. (1997). Medical conditions associated with autism In D. Cohen & F. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 388-410). New York John Wiley & Sons.

Eaves, L. C., Wingert, H., & Ho, H. H. (2006a). Screening for autism: agreement with diagnosis. *Autism, 10*(3), 229-242.

Eaves, L. C., Wingert, H. D., Ho, H. H., & Mickelson, E. C. (2006b). Screening for autism spectrum disorders with the social communication questionnaire. *Journal of Development and Behavioural Paediatrics, 27*(2 Suppl), S95-S103.

Eastern Regional Health Authority (2002). *Review of Services for Persons with Autism Spectrum Disorder in the Eastern Region. Education for Persons with Special Educational Needs Act 2004.* Government Publications

Education Act (1998). Act No 51 of 1998.

Education (Welfare) Act (2000). Act No 8 of 2000.

Ehlers, S., & Gillberg, C. (1993). The epidemiology of Asperger syndrome. A total population study. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 34*(8), 1327-1350.

Ehlers, S., Gillberg, C., & Wing, L. (1999). A screening questionnaire for Asperger syndrome and other high-functioning autism spectrum disorders in school age children. *Journal of Autism and Developmental Disorders, 29*(2), 129-141.

Eisenberg, L., & Kanner, L. (1956). Childhood schizophrenia; symposium, 1955. VI. Early infantile autism, 1943-55. *The American Journal of Orthopsychiatry, 26*(3), 556-566.

Eisenmajer, R., Prior, M., Leekam, S., Wing, L., Gould, J., Welham, M., & Ong, B. (1996). Comparison of clinical symptoms in autism and Asperger's disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*(11), 1523-1531.

Eisenmajer, R., Prior, M., Leekam, S., Wing, L., Ong, B., Gould, J., & Welham, M. (1998). Delayed language onset as a predictor of clinical symptoms in pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 28*(6), 527-533.

Ellefsen, A., Kampmann, H., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2007). Autism in the Faroe Islands: an epidemiological study. *Journal of Autism and Developmental Disorders, 37*(3), 437-444.

Elliott, L. D. (1996). *The British Ability Scales II* Windsor, Berkshire, UK: Nelson Publishing Company.

Epsen Act (2004). *Education for Persons with Special Education Needs*.

Equal Status Act (2000) Act. Act No 8 of 2000.

European Commission (2005). Health & Consumer Protection Directorate General, Directorate C – Public Health Risk Assessment, *Some elements about the prevalence of autism spectrum disorders (ASD) in the European Union*.

Ferketich, S. (1990). Focus on psychometrics. Internal consistency estimates of reliability. *Research in Nursing & Health, 13*(6), 437-440.

Field, A. P. (2005). *Discovering statistics using SPSS.* London Sage.

Filipek, P. A., Accardo, P. J., Ashwal, S., Baranek, G. T., Cook, E. H., Jr., Dawson, G., . . . Volkmar, F. R. (2000). Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology, 55*(4), 468-479.

Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook, E. H., Jr., Dawson, G., Gordon, B., . . . Volkmar, F. R. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders, 29*(6), 439-484.

Fine, M. J., Auble, T. E., Yealy, D. M., Hanusa, B. H., Weissfeld, L. A., Singer, D. E., . . . Kapoor, W. N. (1997). A prediction rule to identify low-risk patients with community-acquired pneumonia. *The New England Journal of Medicine, 336*(4), 243-250.

Firth, U. (2001). What framework should we use for understanding developmental disorders? *Developmental Neuropsychology, 20* 555-563.

Firth, U., Soares, I., & Wing, L. (1993). Research into the earliest detachable signs of autism: "What parents say". *Communication, 27* (3), 17-18

Fitzgerald, M., Matthews, P., & Birkbeck, G. (2002). Maternal burden in families with children with Autistic Spectrum Disorder. *The Irish Journal of Psychology, 33*(2), 1-2

Fitzgerald, M., Matthews, P., Birkbeck, G., & O'Connor, J. (1997). Irish Families Under Stress, Volume 6. A prevalence on psychosocial study in the Eastern Health Board area of Dublin. Eastern Health Board: Dublin.

Flanagan, K. S., Bierman, K. L., & Kam, C. M. (2003). Identifying at-risk children at school entry: the usefulness of multi-behavioural problem profiles. *Journal of Clinical Child and Adolescent Psychology, 32*(3), 396-407.

Fletcher, J. M., & Satz, P. (1984). Test-based versus teacher-based predictions of academic achievement: a three-year longitudinal follow-up. *Journal of Paediatric Psychology, 9*(2), 193-203.

Fombonne, E. (2002). Prevalence of childhood disintegrative disorder. *Autism, 6*(2), 149-157.

Fombonne, E. (1991). The use of questionnaires in child psychiatry research: measuring their performance and choosing an optimal cut-off. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 32*(4), 677-693.

Fombonne, E. (1992). Diagnostic assessment in a sample of autistic and developmentally impaired adolescents. *Journal of Autism and Developmental Disorders, 22*(4), 563-581.

Fombonne, E. (2002). Epidemiological trends in rates of autism. *Molecular Psychiatry, 7 Suppl 2*, S4-6.

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism and Developmental Disorders, 33*(4), 365-382.

Fombonne, E. (2003). The prevalence of autism. *JAMA, 289*(1), 87-89.

Fombonne, E. (2005). Epidemiology of autistic disorder and other pervasive developmental disorders. *The Journal of Clinical Psychiatry, 66 Suppl, 10*, 3-8.

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Paediatric Research, 65*(6), 591-598.

Fombonne, E., Marcin, C., Bruno, R., Tinoco, C. M., & Marquez, C. D. (2012). Screening for autism in Mexico. *Autism Research 5*(3), 180-189.

Fombonne, E., & Tidmarsh, L. (2003). Epidemiologic data on Asperger disorder. *Child & Adolescent Psychiatric Clinics of North America, 12*(1), 15-21.

Freeman, B. J., & Cronin, P. (2002). Diagnosing Autism Spectrum Disorder in young children: An Update. *Infants and Young Children, 14*(3), 1-10.

Freeman, B. J., Rahbar, B., Ritvo, E. R., Bice, T. L., Yokota, A., & Ritvo, R. (1991). The stability of cognitive and behavioural parameters in autism: a twelve-year prospective study. *Journal of the American Academy of Child and Adolescent Psychiatry, 30*(3), 479-482.

Frith, U., Soares, I., & Wing, L. (1993). Research into the earliest detachable signs of autism: What parents say. *Communication, 27*(3), 17-18.

Fullerton, J. T. (1993). Evaluation of research studies. Part IV: Validity and reliability--concepts and application. *Journal of Nurse-Midwifery, 38*(2), 121-125.

Furlano, R. I., Anthony, A., Day, R., Brown, A., McGarvey, L., Thomson, M. A., . . . Murch, S. H. (2001). Colonic CD8 and gamma delta T-cell infiltration with epithelial damage in children with autism. *The Journal of Paediatrics, 138*(3), 366-372.

Gadow, K. D., DeVincent, C. J., Pomeroy, J., & Azizian, A. (2004). Psychiatric symptoms in preschool children with PDD and clinic and comparison samples. *Journal of Autism and Developmental Disorders, 34*(4), 379-393.

Gadow, K. D., Devincent, C. J., Pomeroy, J., & Azizian, A. (2005). Comparison of DSM-IV symptoms in elementary school-age children with PDD versus clinic and community samples. *Autism, 9*(4), 392-415.

Georgiades, S., Szatmari, P., Zwaigenbaum, L., Duku, E., Bryson, S., Roberts, W., . . . Mahoney, W. (2007). Structure of the autism symptom phenotype: A proposed multidimensional model. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(2), 188-196.

Geschwind, D. H., Cummings, J. H., & Hollander, E. (1998). Autism screening and diagnostic evaluation: CAN consensus statement. *CNS Spectrums, 3*, 40-49.

Ghaziuddin, M. (2010). Should the DSM V drop Asperger syndrome? *Journal of Autism and Developmental Disorders, 40*(9), 1146-1148.

Ghaziuddin, M., & Mountain-Kimchi, K. (2004). Defining the intellectual profile of Asperger Syndrome: comparison with high-functioning autism. *Journal of Autism and Developmental Disorders, 34*(3), 279-284.

Gilbridge, K. E. (1995). Developmental testing *Paediatrics in Review, 16*, 338-345.

Gilchrist, A., Green, J., Cox, A., Burton, D., Rutter, M., & Le Couteur, A. (2001). Development and current functioning in adolescents with Asperger syndrome: a comparative study. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 42*(2), 227-240.

Gillberg, C. (1989). Asperger syndrome in 23 Swedish children. *Developmental Medicine and Child Neurology, 31*(4), 520-531.

Gillberg, C., Aicardi, J., & Bax, M. (2009). Neurological and behavioural aspects of genetic anomalies and dysmorphic syndromes including some 'behavioural phenotype syndromes. In J. Aicardi (Ed.), *Diseases of the Nervous System in Childhood* (3rd ed., pp. 137-166). London Kapitel.

Gillberg, C., Ehlers, S., Schaumann, H., Jakobsson, G., Dahlgren, S. O., Lindblom, R., . . . Blidner, E. (1990). Autism under age 3 years: a clinical study of 28 cases referred for autistic symptoms in infancy. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 31*(6), 921-934.

Gillberg, I. C., & Gillberg, C. (1989). Asperger syndrome--some epidemiological considerations: a research note. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 30*(4), 631-638.

Gillberg, C., & Heijdal, H. (1998). MMR and Autism, *Autism, 2*(4), 423-424

Gillberg, C., & Wing, L. (1999). Autism: not an extremely rare disorder. *Acta Psychiatrica Scandinavica, 99*(6), 399-406.

Gilliam, J. E. (1995). *Gilliam Autism Rating Scale (GARS)*. Austin, TX: Pro-Ed.

Glascoe, F. P. (1997). Parents' concerns about children's development: pre-screening technique or screening test? *Paediatrics, 99*(4), 522-528.

Glascoe, F. P. (1999). Using parents' concerns to detect and address developmental and behavioural problems. *Journal of the Society of Paediatric Nurses, 4*(1), 24-35.

Glover, T. A., & Albers, C. A. (2007). Consideration for evaluating universal screening instruments. *Journal of School Psychology, 45*, 117-135

Gadow, K. D., DeVincent, C. J., Pomeroy, J., & Azizian, A. (2004). Psychiatric symptoms in preschool children with PDD and clinic and comparison samples. [Comparative Study]. *Journal of Autism and Developmental Disorders, 34*(4), 379-393.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*(5), 439-451.

Goldberg, W. A., Osann, K., Filipek, P. A., Laulhere, T., Jarvis, K., Modahl, C., . . . Spence, M. A. (2003). Language and other regression: assessment and timing. *Journal of Autism and Developmental Disorders, 33*(6), 607-616.

Goodman, R., Ford, T., Simmons, H., Gatward, R., & Meltzer, H. (2000). Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *The British Journal of Psychiatry, 177*, 534-539.

Gray, M. (2004). Screening in England - Programme Director's Report. Period Summer 2003-Spring 2004. London National Screening Committee.

Gredler, G. R. (2000b). Early childhood screening for developmental and educational problems. In B. A. Bracken (Ed.), *The psycho educational assessment of preschool children* (3rd ed., pp. 399-411). MA: Needham Heights, Allyn & Bacon.

Griffiths, R. (1984). The Abilities of Young Children. Implementation Report. Plan for the Phased EPSEN Act 2004: National Council for Special Education.

Griffiths R. (1996*). Griffiths Mental Developmental Scales - Extended Revised 2 to 8 years*. Hogefe Publications.

Health Act (2004) Act No 42 of 2004.

Health Services Executive (2008). National Review of Autism Services Past, Present and Way Forward Health Services.

Guadagnoli, E., & Velicer, W. F. (1988). Relation of sample size to the stability of component patterns. *Psychological Bulletin, 103*(2), 265-275.

Hagberg, B., Aicardi, J., Dias, K., & Ramos, O. (1983). A progressive syndrome of autism, dementia, ataxia, and loss of purposeful hand use in girls: Rett's syndrome: report of 35 cases. *Annals of Neurology, 14*(4), 471-479.

Hagerman, R., Au, J., & Hagerman, P. (2011). FMR1 permutation and full mutation molecular mechanisms related to autism. *Journal of Neurodevelopment Disorders, 3*(3), 211-224.

Hall, D. B., & Elliman, D. (2003). *Health of all Children* Oxford University Press.

Hall, D. M. B. (1996). *Health for all Children.* Oxford University Press.

Halpern, E. J., Albert, M., Krieger, A. M., Metz, C. E., & Maidment, A. D. (1996). Comparison of receiver operating characteristic curves on the basis of optimal operating points. *Academic Radiology, 3*(3), 245-253.

Hamilton, S. (2006). Screening for developmental delay: reliable, easy-to-use tools. *The Journal of Family Practice, 55*(5), 415-422.

Hanley, J. A., & McNeil, B. J. (1982). The meaning and use of the area under a receiver operating characteristic (ROC) curve. *Radiology, 143*(1), 29-36.

Harris, S. L., & Handleman, J. S. (2000). Age and IQ at intake as predictors of placement for young children with autism: a four- to six-year follow-up. *Journal of Autism and Developmental Disorders, 30*(2), 137-142.

Hayes, S., Richard, D. C., & Kubany, E. S. (1995). Content validity in psychological assessment: a functional approach to concepts and methods. *Psychological Assessment, 7*, 238-247.

Hayes, S. C., Nelson, R. O., & Jarrett, R. B. (1987). The treatment utility of assessment. A functional approach to evaluating assessment quality. *The American Psychologist, 42*(11), 963-974.

Health Services Executive (2009). Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18. HSE.

Health Services Executive (2012). National Review of Autism Services Past, Present and Way Forward, HSE.

Heller. T. (1908) Uber dementia infantilis. Z Erforsch Behandl Jugndl Schwachsinns, 2, 17-28.

Herndon, A. C., DiGuiseppi, C., Johnson, S. L., Leiferman, J., & Reynolds, A. (2009). Does nutritional intake differ between children with autism spectrum disorders and children with typical development? *Journal of Autism and Developmental Disorders, 39*(2), 212-222.

Hippler, K., & Klicpera, C. (2003). A retrospective analysis of the clinical case records of 'autistic psychopaths' diagnosed by Hans Asperger and his team at the University Children's Hospital, Vienna. *Philosophical transactions of the Royal Society of London. Series B, Biological Sciences, 358*(1430), 291-301.

Ho, A., Todd, R. D., & Constantino, J. N. (2005). Brief report: autistic traits in twins vs. non-twins--a preliminary study. *Journal of Autism and Developmental Disorders, 35*(1), 129-133.

Holzer, L., Mihailescu, R., Rodrigues-Degaeff, C., Junier, L., Muller-Nix, C., Halfon, O., & Ansermet, F. (2006). Community introduction of practice parameters for autistic spectrum disorders: Advancing early recognition. *Journal of Autism and Developmental Disorders, 36*(2), 249-262.

Hoshino, Y., Kaneko, M., Yashima, Y., Kumashiro, H., Volkmar, F. R., & Cohen, D. J. (1987). Clinical features of autistic children with setback course in their infancy. *The Japanese Journal of Psychiatry and Neurology, 41*(2), 237-245.

Howlin, P. (1998). Practitioner review: psychological and educational treatments for autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 39*(3), 307-322.

Howlin, P. (2003). Outcome in high-functioning adults with autism with and without early language delays: implications for the differentiation between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders, 33*(1), 3-13.

Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. *Developmental Medicine and Child Neurology 41*(12), 834-839.

Howlin, P., & Karpf, J. (2004). Using the social communication questionnaire to identify 'autistic spectrum' disorders associated with other genetic conditions: findings from a study of individuals with Cohen syndrome. *Autism, 8*(2), 175-182.

Inglese, M. D., & Elder, J. H. (2009). Caring for children with autism spectrum disorder, part 1: prevalence, etiology, and core features. *Journal of Paediatric Nursing 24*(1), 41-48

Institute of Health Clinical Excellence, N. (2012). Autism: The NICE Guideline on Recognition, Referral, Diagnosis and Management of adults on the Autism Spectrum London. The British Psychological Society and The Royal College of Psychiatrists.

Itzchak, E. B., & Zachor, D. A. (2009). Change in Autism Classification with Early Intervention: Predictors and Outcomes. *Research in Autism Spectrum Disorders, 3*(4), 967-976.

Johnson, K. P., Giannotti, F., & Cortesi, F. (2009). Sleep patterns in autism spectrum disorders. *Child & Adolescent Psychiatric Clinics of North America, 18*(4), 917-928.

Johnson, S., Hollis, C., Hennessy, E., Kochhar, P., Wolke, D., & Marlow, N. (2011). Screening for autism in preterm children: diagnostic utility of the Social Communication Questionnaire. *Archives of Disease in Childhood, 96*(1), 73-77.

Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. *Paediatrics, 120*(5), 1183-1215.

Jolliffe, I. T. (1972). Discarding variables in a principal component analysis I: artiÆcial data. *Applied Statistics 21*, 160-173.

Jolliffe, I. T. (1986). *Principals Components Analysis, Series in Statistics* New York Springer.

Jure, R., Rapin, I., & Tuchman, R. F. (1991). Hearing impaired autistic children. *Developmental Medicine & Child Neurology, 33*(12), 1062-1072.

Kaiser, H. F. (1960). The application of electronic computers to factor analysis. *Education and Psychological Measurement, 20*, 141-151

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child 2*, 217-250

Kanner, L., & Eisenberg, L. (1956). Child psychiatry; mental deficiency. *The American Journal of Psychiatry 112*(7), 531-534.

Kawasaki, Y., Yokota, K., Shinomiya, M., Shimizu, Y., & Niwa, S. (1997). Brief report: electroencephalographic paroxysmal activities in the frontal area emerged in middle childhood and during adolescence in a follow-up study of autism. *Journal of Autism and Developmental Disorders, 27*(5), 605-620.

Kazuo, N., Henry, L., & Lambert, N. (2011). *AAMR Adaptive Behaviour Scale Residential & Community: ABS-RS: 2.* Pro-Ed, Inc.

Kerbeshian, J., & Burd, L. (1986). Asperger's syndrome and Tourette syndrome: the case of the pinball wizard. *The British Journal of Psychiatry, 148*, 731-736.

Kerr, A. M., Belichenko, P., Woodcock, T., & Woodcock, M. (2001). Mind and brain in Rett disorder. *Brain & Development, 23 Suppl 1*, S44-49.

Kielinen, M., Rantala, H., Timonen, E., Linna, S. L., & Moilanen, I. (2004). Associated medical disorders and disabilities in children with autistic disorder: a population-based study. *Autism, 8*(1), 49-60.

Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., . . . Grinker, R. R. (2011). Prevalence of autism spectrum disorders in a total population sample. *The American Journal of Psychiatry, 168*(9), 904-912.

Kleinman, J. M., Ventola, P. E., Pandey, J., Verbalis, A. D., Barton, M., Hodgson, S., . . . Fein, D. (2008). Diagnostic stability in very young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(4), 606-615.

Klin, A. (1993). Auditory brainstem responses in autism: brainstem dysfunction or peripheral hearing loss? *Journal of Autism and Developmental Disorders, 23*(1), 15-35.

Klin, A., McPartland, J., & Volkmar, F. R. (2005). Asperger Syndrome In F. R. Volkmar, A. Paul, D. Klin & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders: Vol 1. Diagnosis, development, neurobiology, and behaviour* (3rd ed., pp. 88-125). NJ: John Wiley & Son.

Klin, A., Saulnier, C., Tsatsanis, K., & Volkmar, F. R. (2005). Three diagnostic approaches to Asperger syndrome: Implications for research. *Journal of Autism and Developmental Disorders, 35*, 221-234.

Knaus, W., Wagner, D., & Draper, E. (1991). The APACHE III prognostic system. Risk prediction of hospital mortality for critically ill hospitalized adults (Vol. 100 pp. 1619-1636): Crest.

Kobayashi, R., Murata, T., & Yoshinaga, K. (1992). A follow-up study of 201 children with autism in Kyushu and Yamaguchi areas, Japan. *Journal of Autism and Developmental Disorders, 22*(3), 395-411.

Koegel, L. K., Koegel, R. L., Nefdt, N., Fredeen, R., Klein, E. F., & Bruinma, Y. E. M. (2005). First STEP: A model of early identification of Children with Autism Spectrum Disorders. *Journal of Positive Behaviour Interventions, 7*(4), 247-252.

Konstantareas, M. M., & Homatidis, S. (1999). Chromosomal abnormalities in a series of children with autistic disorder. *Journal of Autism and Developmental Disorders, 29*(4), 275-285.

Koplan, E. K., J. Delis, D. Morris, R. (2004). Weshler Intelligence Scale for Children - Fourth Edition (4th ed.): Peason Assessments.

Kopra, K., von Wendt, L., Nieminen-von Wendt, T., & Paavonen, E. J. (2008). Comparison of diagnostic methods for asperger syndrome. *Journal of Autism and Developmental Disorders, 38*(8), 1567-1573.

Koyama, T., Tachimori, H., Osada, H., Takeda, T., & Kurita, H. (2007). Cognitive and symptom profiles in Asperger's syndrome and high-functioning autism. *Psychiatry and Clinical Neurosciences, 61*(1), 99-104.

Kraemer, H. C., Shrout, P. E., & Rubio-Stipec, M. (2007). Developing the diagnostic and statistical manual V: what will "statistical" mean in DSM-V? *Social Psychiatry & Psychiatric Epidemiology, 42*(4), 259-267.

Kugathasan, S. (2001). Paediatric inflammatory bowel disease: clinical and therapeutic aspects. *Current Opinion in Gastroenterology, 17*(4), 350-355.

Kundel, H. L., & Polansky, M. (2003). Measurement of observer agreement. *Radiology, 228*(2), 303-308.

Kurita, H. (1985). Infantile autism with speech loss before the age of thirty months. *Journal of the American Academy of Child Psychiatry, 24*(2), 191-196.

Lambert, N. N., K. (1993). *Adaptive Behaviour Scale - School Age. (Complete Ref)*

Landa, R. J. (2005). Change in autistic diagnostic classification and symptoms from 14 to 24 months of age. *Paper presented at the Society for Research in Child Development Biennial Meeting,* Atlanta.

Landa, R. J., Holman, K. C., & Garrett-Mayer*, E. (2007).* Social and communication development in toddlers with early and later diagnosis of autism spectrum disorders. *Archives of General Psychiatry, 64(7), 853-864.*

Lauritsen, M., Mors, O., Mortensen, P. B., & Ewald, H. (1999). Infantile autism and associated autosomal chromosome abnormalities: a register-based study and a literature survey. *Journal of Child Psychology and Psychiatry, and Allied Disciplines 40*(3), 335-345.

Law, J., Boyle, J., Harris, F., Harkness, A., & Nye, C. (1998). Screening for primary speech and language delay: a systematic review of the literature. *International Journal of Language & Communication Disorders, 33 Suppl*, 21-23.

Law, J., Boyle, J., Harris, F., Harkness, A., & Nye, C. (2000). The feasibility of universal screening for primary speech and language delay: findings from a systematic review of the literature. *Developmental Medicine and Child Neurology, 42*(3), 190-200.

Le Couteur, A., Bailey, A., Goode, S., Pickles, A., Robertson, S., Gottesman, I., & Rutter, M. (1996). A broader phenotype of autism: the clinical spectrum in twins. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 37*(7), 785-801.

Le Couteur, A., & Baird, G. (2003). National Initiative for Autism Screening and Assessment (NIASA). National Autism Plan for Children: Plan for Identification, Assessment, Diagnosis and Access to Early Intervention for Pre-School and Primary School Aged Children with Autism Spectrum disorders. London National Autistic Society.

Le Couteur, A., Rutter, M., Lord, C., Rios, P., Robertson, S., Holdgrafer, M., & McLennan, J. (1989). Autism diagnostic interview: a standardized investigator-based instrument. *Journal of Autism and Developmental Disorders, 19*(3), 363-387.

Lecavalier, L. (2006). Behavioural and emotional problems in young people with pervasive developmental disorders: relative prevalence, effects of subject characteristics, and empirical classification. *Journal of Autism and Developmental Disorders, 36*(8), 1101-1114.

Lecavalier, L., Aman, M. G., Scahill, L., McDougle, C. J., McCracken, J. T., Vitiello, B., . . . Kau, A. S. (2006). Validity of the autism diagnostic interview-revised. *American Journal of Mental Retardation, 111*(3), 199-215.

Lee, L.-C., David, A. B., Rusyniak, J., Landa, R., & Newschaffer, C. J. (2007). Performance of the Social Communication Questionnaire in children receiving preschool special education services. *Research in Autism Spectrum Disorders, 1*(2), 126-138.

Levy, S. E., Mandell, D. S., & Schultz, R. T. (2009). Autism. *Lancet, 374*(9701), 1627-1638.

Lipkin, P. H. (1991). Epidemiology of the developmental disabilities. In A. J. Capute & P. J. Accardo (Eds.), *Developmental Disabilities in Infancy and Childhood* (pp. 43-67). Baltimore Paul H Brookes Co.

Lord, C. Storoschuk, S. Rutter, M. Pickels, A. . (1993). Using the ADI-R to diagnose autism in preschool children. *Infant Mental Health Journal 14*, 234-252

Lord, C. (1995). Follow-up of two-year-olds referred for possible autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 36*(8), 1365-1382.

Lord, C. (1998). *The Autism Diagnostic Observation Schedule-Generic (ADOS-G)*. Paper presented at the NIH State of the Science in Autism Screening & Diagnosis Working Conference, Bethesda, MD.

Lord, C. (2011). Epidemiology: How common is autism? *Nature, 474*(7350), 166-168.

Lord, C., Leventhal, B. L., & Cook, E. H., Jr. (2001). Quantifying the phenotype in autism spectrum disorders. *American Journal of Medical Genetics, 105*(1), 36-38.

Lord, C., & McGee, J. P. (2001). Educating Children with Autism (Washington DC). Committee on Educational Interventions for Children With Autism, Division of Behavioural and Social Sciences and Education, National Research Council.

Lord, C., & Pickles, A. (1996). Language level and nonverbal social-communicative behaviours in autistic and language-delayed children. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*(11), 1542-1550.

Lord, C., & Risi, S. (1998). Frameworks and methods in diagnosing autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 4*, 90-96.

Lord, C., Risi, S., DiLavore, P. C., Shulman, C., Thurm, A., Pickles, A., . . . Griffiths, P. (2006). Screening for autism in pre-school children in primary care: Systematic review of English language tools. *International Journal of Nursing Studies, 43*(5), 623-636.

Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry, 63*(6), 694-701.

Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr., Leventhal, B. L., DiLavore, P. C., . . . Rutter, M. (2000). The autism diagnostic observation schedule-generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders, 30*(3), 205-223.

Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (1999). Autism Diagnostic Observation Schedule. Los Angeles, CA: Western Psychological Services.

Lord, C., Rutter, M., Goode, S., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, E. (1989). Autism diagnostic observation schedule: a standardized observation of communicative and social behaviour. *Journal of Autism and Developmental Disorders, 19*(2), 185-212.

Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 24*(5), 659-685.

Lord, C. S., S. Rutter, M. Pickels, A. (1993). Using the ADI-R to diagnose autism in preschool children. *Infant Mental Health Journal, 14*, 234-252.

Lord, C., & Schopler, E. (1989). The role of age at assessment, developmental level, and test in the stability of intelligence scores in young autistic children. *Journal of Autism and Developmental Disorders, 19*(4), 483-499.

Lotter, V. (1974). Factors related to outcome in autistic children. *Journal of Autism and Childhood Schizophrenia, 4*(3), 263-277.

Loveland, K. A., & Tunali-Kotoski, B. (1997). The school age child with autism. In D. Cohen & F. R. Volkmar (Eds.), *Handbook of Autism and Pervasive Developmental Disorders* (2nd ed., pp. 283-308). New York.

Luyster, R., Richler, J., Risi, S., Hsu, W. L., Dawson, G., Bernier, R., . . . Lord, C. (2005). Early regression in social communication in autism spectrum disorders: a CPEA Study. *Developmental Neuropsychology, 27*(3), 311-336.

Macintosh, K. E., & Dissanayake, C. (2004). Annotation: The similarities and differences between autistic disorder and Asperger's disorder: a review of the empirical evidence. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 45*(3), 421-434.

Magiati, I., & Howlin, P. (2001). Monitoring the progress of preschool children with autism enrolled in early intervention programmes: problems in cognitive assessment. *Autism, 5*(4), 399-406.

Magyar, C. I., Pandol fi, V., & Dill, C. A. (2012). An initial evaluation of the Social Communication Questionnaire for the assessment of autism spectrum disorders in children with Down syndrome. *Journal of Development and Behavioural Paediatrics 33*(2), 134-145.

Mahler, M. S., & Furer, M. (1972). Child psychosis: a theoretical statement and its implications. *Journal of Autism and Childhood Schizophrenia, 2*(3), 213-218.

Mahoney, W. J., Szatmari, P., MacLean, J. E., Bryson, S. E., Bartolucci, G., Walter, S. D., . . . Zwaigenbaum, L. (1998). Reliability and accuracy of differentiating pervasive developmental disorder subtypes. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*(3), 278-285.

Majnemer, A. (1998). Benefits of early intervention for children with developmental disabilities. *Seminars in Paediatric Neurology, 5*(1), 62-69.

Malhorta, S., & Singh, S. (1993). Childhood Disintegrative Disorder. *Journal of Autism and Developmental Disorders, 29* 491 – 498.

Malow, B. A., Marzec, M. L., McGrew, S. G., Wang, L., Henderson, L. M., & Stone, W. L. (2006). Characterizing sleep in children with autism spectrum disorders: a multidimensional approach. *Sleep, 29*(12), 1563-1571.

Mandell, D. S., & Palmer, R. (2005). Differences among states in the identification of autistic spectrum disorders. *Archives of Paediatrics & Adolescent Medicine, 159*(3), 266-269.

Manjiviona, J., & Prior, M. (1995). Comparison of Asperger syndrome and high-functioning autistic children on a test of motor impairment. *Journal of Autism and Developmental Disorders, 25*(1), 23-39.

Manning-Courtney, P., Murray, D., Currans, K., Johnson, H., Bing, N., Kroeger-Geoppinger, K., . . . Messerschmidt, T. (2013). Autism spectrum disorders. *Current Problems Paediatric Adolescent Health Care, 43*(1), 2-11.

Marrie, T. J., Lau, C. Y., Wheller, S. L., Wong, C. J., Vandervoort, M. K., & Feagan, B. G. (2000). A controlled trial of a critical pathway for treatment of community-acquired pneumonia. *JAMA, 283,* 749-755.

Matijevic, T., Knezevic, J., Slavica, M., & Pavelic, J. (2009). Rett syndrome: from the gene to the disease. *European Neurology, 61*(1), 3-10.

Mawle, E., & Griffiths, P. (2006). Screening for autism in pre-school children in primary care: systematic review of English Language tools. *International Journal of Nursing Studies, 43*(5), 623-636.

Mayes, L., Volkmar, F., Hooks, M., & Cicchetti, D. (1993). Differentiating pervasive developmental disorder not otherwise specified from autism and language disorders. *Journal of Autism and Developmental Disorders, 23*(1), 79-90.

Mayes, S. D., & Calhoun, S. L. (2003). Analysis of WISC-III, Stanford-Binet:IV, and academic achievement test scores in children with autism. *Journal of Autism and Developmental Disorders, 33*(3), 329-341.

McAtee, M., Carr, E. G., Schulte, C., & Dunlap, G. A. (2004). A contextual assessment inventory for problem behaviour: initial development. *Journal of Positive Behaviour Interventions, 6*(3), 148-165.

McConachie, H., Le Couteur, A., & Honey, E. (2005). Can a diagnosis of Asperger syndrome be made in very young children with suspected autism spectrum disorder? *Journal of Autism and Developmental Disorders, 35*(2), 167-176.

McDonald, L., Rennie, A., Tolmie, J., Galloway, P., & McWilliam, R. (2006). Investigation of global developmental delay. *Archives of Disease in Childhood, 91*(8), 701-705.

Medical Research Council (2001). *Review of Autism Research*. London: MRC.

Meier, J. H. (1975). Screening, assessment and intervention for young children at developmental risk. In N. Hobb (Ed.), *Issues in the classification of children, Vol 2*. San Francisco Jossey-Bass.

Mercer, C. D., Algozzine, B., & Triffiletti, J. (1988). Early identification – an analysis of the research. *Learning Disability Quarterly 11*, 176-188.

Mesibov, G., & Handlan, S. (1997). Adolescents and adults with autism. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of Autism and Pervasive Developmental Disorders* (2nd ed., pp. 309-324). New York John Wiley & Sons.

Messick, S. (1989). Validity In R. L. Linn (Ed.), *Educational measurement* (3rd ed., pp. 13-103). New York Macmillan.

Messick, S. (1995). Validation of inferences from persons and performance as scientific inquiry into score something. *American Psychologist, 50,* 741-749.

Michelotti, J., Charman, T., Slonims, V., & Baird, G. (2002). Follow-up of children with language delay and features of autism from preschool years to middle childhood. *Developmental Medicine and Child Neurology, 44*(12), 812-819.

Miles, J. H., & Hillman, R. E. (2000). Value of a clinical morphology examination in autism. *American Journal of Medical Genetics, 91*(4), 245-253.

Militerni. R, Bravaccio, C., & D'Aunono, P. (1997). Childhood Disintegrative Disorder: Review of cases and pathological consideration. *Developmental Brain Dysfunction, 10,* 67-74.

Miller, J. N., & Ozonoff, S. (1997). Did Asperger's cases have Asperger disorder? A research note. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 38*(2), 247-251.

Ming, X., Gordon, E., Kang, N., & Wagner, G. C. (2008). Use of clonidine in children with autism spectrum disorders. *Brain & Development, 30*(7), 454-460.

Minshew, N. J., & Goldstein, G. (2001). The pattern of intact and impaired memory functions in autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 42*(8), 1095-1101.

Minshew, N. J., Sweeney, J. A., & Bauman, M. L. (1997). Neurologic aspects of autism. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of Autism and Pervasive Developmental Disorders* (2nd ed., pp. 344 -369). New York John Wiley & Sons.

Moore, V., & Goodson, S. (2003). How well does early diagnosis of autism stand the test of time? Follow-up study of children assessed for autism at age 2 and development of an early diagnostic service. *Autism, 7*(1), 47-63.

Moss, J., & Howlin, P. (2009). Autism spectrum disorders in genetic syndromes: implications for diagnosis, intervention and understanding the wider autism spectrum disorder population. *Journal of Intellectual Disability Research, 53*(10), 852-873.

Moss, J., Magiati, I., Charman, T., & Howlin, P. (2008). Stability of the autism diagnostic interview-revised from pre-school to elementary school age in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(6), 1081-1091.

Mouridsen, S. E., Rich, B., & Isager, T. (1998). Validity of childhood disintegrative psychosis. General findings of a long-term follow-up study. *The British Journal of Psychiatry, 172*, 263-267.

Mouridsen, S. E., Rich, B., & Isager, T. (2000). A comparative study of genetic and neurobiological findings in disintegrative psychosis and infantile autism. *Psychiatry and Clinical Neurosciences, 54*(4), 441-446.

Muhle, R., Trentacoste, S. V., & Rapin, I. (2004). The genetics of autism. *Paediatrics, 113*(5), e472-486.

Mulligan, A., Richardson, T., Anney, R. J., & Gill, M. (2009). The Social Communication Questionnaire in a sample of the general population of school-going children. *Irish Journal of Medical Science, 178*(2), 193-199.

Mundy, P., & Markus, J. (1997). On the Nature of Communication and Language Impairment in Autism. *Mental Retardation and Developmental Disabilities, 3*, 343-349

Mundy, P., & Sigman, M. (1989b). The theoretical implications of joint attention deficits in autism. *Development & Psychopathology, 1*, 173-183.

Mundy, P., Sigman, M., & Kasari, C. (1990). A longitudinal study of joint attention and language development in autistic children. *Journal of Autism and Developmental Disorders, 20*(1), 115-128.

Mundy, P., Sigman, M., & Kasari, C. (1993). The theory of mind and joint-attention deficits in autism. In S. Cohen & H. Tagar-Flusberg (Eds.), *Understanding Other Minds: Perspectives from Autism*. Oxford University Press.

Munro, B. H. (2005). *Statistical methods for health care research*. Philadelphia Lippincott, Williams & Wilkins.

Murray, H. A. (1938). *Explorations in personality* New York, Oxford University Press.

Murray, M. J., Mayes, S. D., & Smith, L. A. (2011). Brief report: excellent agreement between two brief autism scales (Checklist for Autism Spectrum Disorder and Social Responsiveness Scale) completed independently by parents and the Autism Diagnostic Interview-Revised. *Journal of Autism and Developmental Disorders, 41*(11), 1586-1590.

Myers, S. M., & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Paediatrics, 120*(5), 1162-1182.

Nagy, J., & Szatmari, P. (1986). A chart review of schizotypal personality disorders in children. *Journal of Autism and Developmental Disorders, 16*(3), 351-367.

National Disability Authority (2003). Review of access to mental health services for people with intellectual disabilities.

National Research Council. (2001). *Committee on Interventions for Children with Autism, Educating Children with Autism,* Washington DC: National Academic Press.

National Screening Committee. (1998). First Report of the National Screening Committee. London Health Department UK.

Second Report of the UK National Screening Committee: Department of Health for England, Scotland, Northern Ireland, and Wales.

Netemeyer, R. G., Bearden, W. O., & Sharma, S. (2003). *Scaling procedures: Issues and applications*. CA: Thousand Oaks, Sage.

Neul, J. L., Fang, P., Barrish, J., Lane, J., Caeg, E. B., Smith, E. O., . . . Glaze, D. G. (2008). Specific mutations in methyl-CpG-binding protein 2 confer different severity in Rett syndrome. *Neurology, 70*(16), 1313-1321.

Newschaffer, C. J., Falb, M. D., & Gurney, J. G. (2005). National autism prevalence trends from United States special education data. *Paediatrics, 115*(3), e277-282.

Nikolov, R. N., Bearss, K. E., Lettinga, J., Erickson, C., Rodowski, M., Aman, M. G., . . . Scahill, L. (2009). Gastrointestinal symptoms in a sample of children with pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 39*(3), 405-413.

Noland, R. M., & Gabriels, R. L. (2004). Screening and identifying children with autism spectrum disorders in the public school system: the development of a model process. *Journal of Autism and Developmental Disorders, 34*(3), 265-277.

Norris, M., & Lecavalier, L. (2010). Screening accuracy of Level 2 autism spectrum disorder rating scales. A review of selected instruments. *Autism, 14*(4), 263-284.

Noterdaeme, M., & Hutzelmeyer-Nickels, A. (2010). Early symptoms and recognition of pervasive developmental disorders in Germany. *Autism, 14*(6), 575-588.

Noterdaeme, M., Mildenberger, K., Sitter, S., & Amorosa, H. (2002). Parent information and direct observation in the diagnosis of pervasive and specific developmental disorders. *Autism, 6*(2), 159-168.

Noterdaeme, M., Wriedt, E., & Hohne, C. (2010). Asperger's syndrome and high-functioning autism: language, motor and cognitive profiles. *European Child & Adolescent Psychiatry, 19*(6), 475-481.

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric Theory*. New York McGraw-Hill.

Oakland, T., & Harrison, P. L. (2008). *Adaptive Behavioural Assessment System II (ABAS)*: Elsevier Inc.

O'Hare, A. (2009). Autism spectrum disorder: diagnosis and management. *Archives of Disease in childhood. Education and Practice Edition, 94*(6), 161-168.

Oliveira, G., Ataide, A., Marques, C., Miguel, T. S., Coutinho, A. M., Mota-Vieira, L., . . . Vicente, A. M. (2007). Epidemiology of autism spectrum disorder in Portugal: prevalence, clinical characterization, and medical conditions. *Developmental Medicine and Child Neurology, 49*(10), 726-733.

Olivie, H. (2012). The medical care of children with autism. *European Journal of Paediatrics, 171*(5), 741-749.

Oosterling, I., Rommelse, N., de Jonge, M., van der Gaag, R. J., Swinkels, S., Roos, S., . . . Buitelaar, J. (2010). How useful is the Social Communication Questionnaire in toddlers at risk of autism spectrum disorder? *Journal of Child Psychology and Psychiatry, and Allied Disciplines 51*(11), 1260-1268.

Ozonoff, S., Goodlin-Jones, B. L., & Solomon, M. (2005). Evidence-based assessment of autism spectrum disorders in children and adolescents. *Journal of Clinical Child and Adolescent Psychology, 34*(3), 523-540.

Ozonoff, S., & McMahon, G. E. (2000). DSM-IV-defined Asperger syndrome: cognitive, behavioural and early history differentiation from high-functioning autism. In F. R. Volkmar & S. Sparrow (Eds.), *Asperger syndrome* (pp. 72-96). New York Guilford Press.

Ozonoff, S., Pennington, B. F., & Rogers, S. J. (1991). Executive function deficits in high-functioning autistic individuals: relationship to theory of mind. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 32*(7), 1081-1105.

Ozonoff, S., South, M., & Miller, J. (2000). DSM-IV-defined Asperger syndrome: cognitive, behavioural and early history differentiation from high-functioning autism. *Autism 4*, 29-46.

Page, T. (2000). Metabolic approaches to the treatment of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 30*(5), 463-469.

Parson, S., Guldberg, K., & MacLeod, A. (2009). International Review of the Literature of Evidence of Best Practice Provision in the Education of Persons with Autism Spectrum Disorders: National Council for Special Education (NCSC).

Pearson, D. A., Loveland, K. A., Lachar, D., Lane, D. M., Reddoch, S. L., Mansour, R., & Cleveland, L. A. (2006). A comparison of behavioural and emotional functioning in children and adolescents with Autistic Disorder and PDD-NOS. *Child Neuropsychology, 12*(4-5), 321-333.

Pine, D. S., Guyer, A. E., Goldwin, M., Towbin, K. A., & Leibenluft, E. (2008). Autism spectrum disorder scale scores in paediatric mood and anxiety disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(6), 652-661.

Pine, E., Luby, J., Abbacchi, A., & Constantino, J. N. (2006). Quantitative assessment of autistic symptomatology in preschoolers. *Autism, 10*(4), 344-352.

Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principals and methods* (7th ed.). Philadelphia Lippincott, Williams & Wilkins.

Posada. M, & Ramirez, A. (2008). European Autism Information System Final Report.

Posey, D. J., Aman, M. G., McCracken, J. T., Scahill, L., Tierney, E., Arnold, L. E., . . . McDougle, C. J. (2007). Positive effects of methylphenidate on inattention and hyperactivity in pervasive developmental disorders: an analysis of secondary measures. *Biological Psychiatry, 61*(4), 538-544.

Posserud, M. B., Lundervold, A. J., & Gillberg, C. (2006). Autistic features in a total population of 7-9-year-old children assessed by the ASSQ (Autism Spectrum Screening Questionnaire). *Journal of Child Psychology and Psychiatry, and Allied Disciplines 47*(2), 167-175.

Posserud, M. B., Lundervold, A. J., & Gillberg, C. (2009). Validation of the autism spectrum screening questionnaire in a total population sample. *Journal of Autism and Developmental Disorders, 39*(1), 126-134.

Posserud, B., Lundervold, A. J., Steijnen, M. C., Verhoeven, S., Stormark, K. M., & Gillberg, C. (2008). Factor analysis of the Autism Spectrum Screening Questionnaire. *Autism, 12*(1), 99-112.

New York Dept of Health Early Intervention Programme. (1999). Clinical Practice Guideline: Report of the Recommendations. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 years).

Rapin, I. (1996). Practitioner review: developmental language disorders: a clinical update. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 37*(6), 643-655.

Rapin, I. (1996). *Preschool children with inadequate communication: developmental language disorder, autism, low IQ* (MacKeith): London.

Reaven, J. A., Hepburn, S. L., & Ross, R. G. (2008). Use of the ADOS and ADI-R in children with psychosis: importance of clinical judgment. *Clinical Child Psychology and Psychiatry, 13*(1), 81-94.

Reich, M., Lenoir, P., Malvy, J., Perrot, A., & Sauvage, D. (1997). Bourneville's tuberous sclerosis and autism. *Archives de Pediatrie, 4*(2), 170-175.

Rett, A. (1966). On a unusual brain atrophy syndrome in hyperammonemia in childhood. *Wien Med Wochenschr, 116*(37), 723-726.

Reynell, J., & Gruber, C. (1990). Reynell Developmental Language Scales Los Angeles Western Psychological Services.

Richdale, A. L. (1999). Sleep problems in autism: prevalence, cause, and intervention. *Developmental Medicine and Child Neurology, 41*(1), 60-66.

Robertson, E. A., Zweig, M. H., & Van Steirteghem, M. D. (1983). Evaluating the clinical accuracy of laboratory tests. *American Journal of Clinical Pathology, 79*, 78-86.

Robins, D. L. (2008). Screening for autism spectrum disorders in primary care settings. *Autism, 12*(5), 537-556.

Roid G (2003). Stanford Binet Intelligence Scales (SB5), 5th Edition, Pro Ed.

Rosenberg, R. E., Daniels, A. M., Law, J. K., Law, P. A., & Kaufmann, W. E. (2009). Trends in autism spectrum disorder diagnoses: 1994-2007. *Journal of Autism and Developmental Disorders, 39*(8), 1099-1111.

Rossi, P. G., Parmeggiani, A., Bach, V., Santucci, M., & Visconti, P. (1995). EEG features and epilepsy in patients with autism. *Brain & Development, 17*(3), 169-174.

Rutter, M. (1984). Autistic children growing up. *Developmental Medicine and Child. Neurology, 26*, 122-129.

Rutter, M. (2011). Research review: Child psychiatric diagnosis and classification: concepts, findings, challenges and potential. *Journal of Child Psychology and Psychiatry, and Allied Disciplines 52*(6), 647-660.

Rutter, M., Bailey, A., Bolton, P., & Le Couteur, A. (1994). Autism and known medical conditions: myth and substance. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 35*(2), 311-322.

Rutter, M., Bailey, A., & Lord, C. (2003). Social Communication Questionnaire Los Angeles Western Psychological Services.

Rutter, M., Bailey, A., Simonoff, E., & Pickles, A. (1997). Genetic influences and autism. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 370-387). New York John Wiley & Sons.

Rutter, M., & Schopler, E. (1987). Autism and pervasive developmental disorders: concepts and diagnostic issues. *Journal of Autism and Developmental Disorders, 17*(2), 159-186.

Rydz, D., Shevell, M. I., Majnemer, A., & Oskoui, M. (2005). Developmental screening. *Journal of Child Neurology, 20*(1), 4-21.

Saulnier, C. A., & Klin, A. (2007). Brief report: social and communication abilities and disabilities in higher functioning individuals with autism and Asperger syndrome. *Journal of Autism and Developmental Disorders, 37*(4), 788-793.

Schnur, J. (2005). Asperger syndrome in children. *Journal of the American Academy of Nurse Practitioners, 17*(8), 302-308.

Schopler, E., Reichler, R., & Rochen-Renner, B. (1988). *The Childhood Autism Rating Scale (CARS)*. Los Angeles, CA: Western Psychological Services.

Schroer, R. J., Phelan, M. C., Michaelis, R. C., Crawford, E. C., Skinner, S. A., Cuccaro, M., . . . Stevenson, R. E. (1998). Autism and maternally derived aberrations of chromosome 15q. *American Journal of Medical Genetics, 76*(4), 327-336.

Schultz, K. S., & Whitney, D. J. (2005). *Measurement theory in action*. CA: Thousand Oaks, Sage.

Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). Brief report: prevalence of autism spectrum conditions in children aged 5-11 years in Cambridgeshire, UK. *Autism, 6*(3), 231-237.

Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). The CAST (Childhood Asperger Syndrome Test): preliminary development of a UK screen for mainstream primary-school-age children. *Autism, 6*(1), 9-31.

Scottish Intercollegiate Guideline Network. (2007). Assessment, diagnosis and clinician interventions for children and young people with autism spectrum disorders. A National Clinical Guideline (SIGN), NHS.

Semel, E., Wiig, E. H., & Secord, W. A. (2003). Clinical evaluation of language fundamentals (CELF) (4th ed). San Antonio, TX Psychological Corporation.

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., . . . Cuniff, C. (2009). Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry, 48*(5), 474-483.

Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., . . . Lord, C. (2007). Change in autism symptoms and maladaptive behaviours in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*(9), 1735-1747.

Shriver, M. D., Allen, K. D., & Matthews, J. R. (1999). Effective assessment of shared and unique characteristics of children with autism. *School Psychology Review, 28*, 538-558.

Siegel, B. (1998). *Early screening and diagnosis in autism spectrum disorders. The Pervasive Developmental Disorders Screening Test (PDDST)*. Paper presented at the NIH State of the Science in Autism. Screening & Diagnosis Working Conference Bethesda, MD.

Siegel, D. J., Minshew, N. J., & Goldstein, G. (1996). Wechsler IQ profiles in diagnosis of high-functioning autism. *Journal of Autism and Developmental Disorders, 26*(4), 389-406.

Sikora, D. M., Hall, T. A., Hartley, S. L., Gerrard-Morris, A. E., & Cagle, S. (2008). Does parent report of behaviour differ across ADOS-G classifications: analysis of scores from the CBCL and GARS. *Journal of Autism and Developmental Disorders, 38*(3), 440-448.

Siperstein, R., & Volkmar, F. (2004). Brief report: parental reporting of regression in children with pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 34*(6), 731-734.

Skuse, D. H. (2000). Imprinting, the X-chromosome, and the male brain: explaining sex differences in the liability to autism. *Paediatric Research, 47*(1), 9-16.

Smalley, S. L., Tanguay, P. E., Smith, M., & Gutierrez, G. (1992). Autism and tuberous sclerosis. *Journal of Autism and Developmental Disorders, 22*(3), 339-355.

Smeets, E., Terhal, P., Casaer, P., Peters, A., Midro, A., Schollen, E., . . . Fryns, J. P. (2005). Rett syndrome in females with CTS hot spot deletions: a disorder profile. *American Journal of Medical Genetics. Part A, 132A*(2), 117-120.

Smith, C. R., & Brees, N. (1983). Autism: Model Projects. Des Moines, Iowa: Department of Public Instruction.

Snow, A. V., & Lecavalier, L. (2008). Sensitivity and specificity of the Modified Checklist for Autism in Toddlers and the Social Communication Questionnaire in preschoolers suspected of having pervasive developmental disorders. *Autism, 12*(6), 627-644.

Snow, A. V., & Lecavalier, L. (2011). Comparing autism, PDD-NOS, and other developmental disabilities on parent-reported behaviour problems: little evidence for ASD subtype validity. *Journal of Autism and Developmental Disorders, 41*(3), 302-310.

Snow, A. V., Lecavalier, L., & Houts, C. (2009). The structure of the Autism Diagnostic Interview-Revised: diagnostic and phenotypic implications. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 50*(6), 734-742.

Sparrow, S., Balla, D., & Cicchetti, D. (1984). Vineland Adaptive Behaviour Scale (VABS) Minnesota American Guidelines Service.

Spence, S. J., Sharifi, P., & Wiznitzer, M. (2004). Autism spectrum disorder: screening, diagnosis, and medical evaluation. *Seminars in Paediatric Neurology, 11*(3), 186-195.

Sponheim, E. (1996). Changing criteria of autistic disorders: a comparison of the ICD-10 research criteria and DSM-IV with DSM-III-R, CARS, and ABC. *Journal of Autism and Developmental Disorders, 26*(5), 513-525.

Sponheim, E., & Skjeldal, O. (1998). Autism and related disorders: epidemiological findings in a Norwegian study using ICD-10 diagnostic criteria. *Journal of Autism and Developmental Disorders, 28*(3), 217-227.

Sponheim, E., & Spurkland, I. (1996). Diagnosing childhood autism in clinical practice: An inter-rater reliability study of ICD-10, DSM-III-R, Childhood Autism Rating Scale, and Autism Behaviour Checklist. *Nordic Journal of Psychiatry, 50* 5-9.

Spreat, S. (1980). The AAMD Adaptive Behaviour Scale - A Study of Criterion Validity. . *American Journal of Mental Deficiency, 85* 61-68.

Squires, J. (1996). Parent-completed developmental questionnaires: A low-cost strategy for child-find and screening Infants and Young. *Infants and Young Children, 9*(1), 16-28.

Ssucharewa, G. E., & Wolff, S. (1996). The first account of the syndrome Asperger described? Translation of a paper entitled "Die schizoiden Psychopathien im Kindesalter" by Dr. G.E. Ssucharewa; scientific assistant, which appeared in 1926 in the Monatsschrift fur Psychiatrie und Neurologie 60:235-261. *European Child & Adolescent Psychiatry 5*(3), 119-132.

Stein, M. T., Klin, A., Miller, K., Goulden, K., Coolman, R., & Coolman, D. M. (2004). When Asperger's syndrome and a nonverbal learning disability look alike. *Journal of Developmental and Behavioural Paediatrics, 25*(3), 190-195.

Stevens, J. P. (1992). *Applied multivariate statistics for the social sciences*. NJ: Erlbaum Hillsdale.

Stevens, M. C., Fein, D. A., Dunn, M., Allen, D., Waterhouse, L. H., Feinstein, C., & Rapin, I. (2000). Subgroups of children with autism by cluster analysis: a longitudinal examination. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*(3), 346-352.

Steyaert, J. G., & De la Marche, W. (2008). What's new in autism? *European Journal of Paediatrics, 167*(10), 1091-1101.

Stone, W. L. (1997). Autism in infancy and early childhood In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of Autism & Pervasive Developmental Disorders* (2nd ed., pp. 266-282). New York Wiley.

Stone, W. L. (1998a). *Descriptive information about the Screening Tool for Autism in Two-Year-Olds (STAT)*. Paper presented at the NIH State of the Science in Autism: Screening & Diagnosis Working Conference, Bethesda, MD.

Stone, W. L. (1998b). *STAT manual: Screening Tool for Autism in Two-Year Olds*. Paper presented at the NIH State of the Science in Autism Screening & Diagnosis Working Conference, Bethesda, MD.

Stone, W. L., & Hogan, K. L. (1993). A structured parent interview for identifying young children with autism. *Journal of Autism and Developmental Disorders, 23*(4), 639-652.

Stone, W. L., Lee, E. B., Ashford, L., Brissie, J., Hepburn, S. L., Coonrod, E. E., & Weiss, B. H. (1999). Can autism be diagnosed accurately in children under 3 years? *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 40*(2), 219-226.

Stone, W. L., & Yoder, P. J. (2001). Predicting spoken language level in children with autism spectrum disorders. *Autism, 5*(4), 341-361.

Sukhodolsky, D. G., Scahill, L., Gadow, K. D., Arnold, L. E., Aman, M. G., McDougle, C. J., . . . Vitiello, B. (2008). Parent-rated anxiety symptoms in children with pervasive developmental disorders: frequency and association with core autism symptoms and cognitive functioning. *Journal of Abnormal Child Psychology, 36*(1), 117-128.

Sunil. (2006). Autism: A review for family physicians. *Indian Journal of Medical Sciences* (60), 205-215.

Szatmari, P. (2000). The classification of autism, Asperger's syndrome, and pervasive developmental disorder. *Canadian Journal of Psychiatry, 45*(8), 731-738.

Szatmari, P., Archer, L., Fisman, S., Streiner, D. L., & Wilson, F. (1995). Asperger's syndrome and autism: differences in behaviour, cognition, and adaptive functioning. *Journal of the American Academy of Child and Adolescent Psychiatry, 34*(12), 1662-1671.

Szatmari, P., Bartolucci, G., & Bremner, R. (1989). Asperger's syndrome and autism: comparison of early history and outcome. *Developmental Medicine and Child Neurology, 31*(6), 709-720.

Szatmari, P., Bryson, S., Duku, E., Vaccarella, L., Zwaigenbaum, L., Bennett, T., & Boyle, M. H. (2009). Similar developmental trajectories in autism and Asperger syndrome: from early childhood to adolescence. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 50*(12), 1459-1467.

Szatmari, P., Georgiades, S., Bryson, S., Zwaigenbaum, L., Roberts, W., Mahoney, W., . . . Tuff, L. (2006). Investigating the structure of the restricted, repetitive behaviours and interests domain of autism. *Journal of Child Psychology and Psychiatry, 47*(6), 582-590.

Szatmari, P., Jones, M. B., Fisman, S., Tuff, L., Bartolucci, G., Mahoney, W. J., & Bryson, S. E. (1995). Parents and collateral relatives of children with pervasive developmental disorders: a family history study. *American Journal of Medical Genetics, 60*(4), 282-289.

Szatmari, P., Merette, C., Bryson, S. E., Thivierge, J., Roy, M. A., Cayer, M., & Maziade, M. (2002). Quantifying dimensions in autism: a factor-analytic study. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(4), 467-474.

Tadevosyan-Leyfer, O., Dowd, M., Mankoski, R., Winklosky, B., Putnam, S., McGrath, L., . . . Folstein, S. E. (2003). A principal components analysis of the Autism Diagnostic Interview-Revised. *Journal of the American Academy of Child and Adolescent Psychiatry 42*(7), 864-872.

Tanguay, P. E., Robertson, J., & Derrick, A. (1998). A dimensional classification of autism spectrum disorder by social communication domains. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*(3), 271-277.

Tantam, D. (1988). Asperger's syndrome. *Journal of Child Psychology and Psychiatry, and Allied Disciplines 29*(3), 245-255.

Teal, M. B., & Wiebe, M. J. (1986). A validity analysis of selected instruments used to assess autism. *Journal of Autism and Developmental Disorders, 16*(4), 485-494.

Tebruegge, M., Nandini, V., & Ritchie, J. (2004). Does routine child health surveillance contribute to the early detection of children with pervasive developmental disorders? An epidemiological study in Kent, U.K. *BMC Paediatrics, 4*, 4.

Tomanik, S. S., Pearson, D. A., Loveland, K. A., Lane, D. M., & Bryant Shaw, J. (2007). Improving the reliability of autism diagnoses: examining the utility of adaptive behavior. *Journal of Autism and Developmental Disorders, 37*(5), 921-928.

Trochim, W. (2005). *Research Methods: The Concise Knowledge Base*. Cincinnati Atomic Dog Publishers.

Tuchman, R. F., & Rapin, I. (1997). Regression in pervasive developmental disorders: seizures and epileptiform electroencephalogram correlates. Paediatrics, 99(4), 560-566.

Tuchman, R. F., Rapin, I., & Shinnar, S. (1991). Autistic and dysphasic children. II: Epilepsy. *Paediatrics, 88*(6), 1219-1225.

Tuchman, R. F., Rapin, I., & Shinnar, S. (1999). Autistic and dysphasic children II: Epilepsy. *Paediatrics, 88*, 1219-1225.

Turner, D. A. (1978). An intuitive approach to receiver operating characteristic curve analysis. *Journal of Nuclear Medicine, 19*(2), 213-220.

Turner, L. M., & Stone, W. L. (2007). Variability in outcome for children with an ASD diagnosis at age 2. *Journal of Child Psychology and Psychiatry, and Allied Disciplines 48*(8), 793-802.

Turner, L. M., Stone, W. L., Pozdol, S. L., & Coonrod, E. E. (2006). Follow-up of children with autism spectrum disorders from age 2 to age 9. *Autism, 10*(3), 243-265.

Valicenti-McDermott, M., McVicar, K., Rapin, I., Wershil, B. K., Cohen, H., & Shinnar, S. (2006). Frequency of gastrointestinal symptoms in children with autistic spectrum disorders and association with family history of autoimmune disease. *Journal of Development and Behavioural Paediatrics, 27*(2 Suppl), S128-136.

Van Erkel, A. R., & Pattynama, P. M. (1998). Receiver operating characteristic (ROC) analysis: basic principles and applications in radiology. *European Journal of Radiology, 27*(2), 88-94.

Van Karnebeek, C. D., Jansweijer, M. C., Leenders, A. G., Offringa, M., & Hennekam, R. C. (2005). Diagnostic investigations in individuals with mental retardation: a systematic literature review of their usefulness. *European Journal of Human Genetics, 13*(1), 6-25.

Van Krevelen, D. A. (1971). Early infantile autism and autistic psychopathy. *Journal of Autism and Childhood Schizophrenia, 1*(1), 82-86.

Van Den Heuvel, A., Fitzgerald, M., Greiner, B., & Perry, I. J. (2007). Screening for autistic spectrum disorder at the 18-month developmental assessment: a population-based study. *Irish Medical Journal, 100*(8), 565-567.

Venter, A., Lord, C., & Schopler, E. (1992). A follow-up study of high-functioning autistic children. *Journal of Child Psychology and Psychiatry, and Allied Disciplines 33*(3), 489-507.

Ventola, P. E., Kleinman, J., Pandey, J., Barton, M., Allen, S., Green, J., . . . Fein, D. (2006). Agreement among four diagnostic instruments for autism spectrum disorders in toddlers. *Journal of Autism and Developmental Disorders, 36*(7), 839-847.

Volkmar, F. R. (1992). Childhood disintegrative disorder: issues for DSM-IV. *Journal of Autism and Developmental Disorders, 22*(4), 625-642.

Volkmar, F. (1999). Can you explain the difference between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders, 29*(2), 185-186.

Volkmar, F. R., Cicchetti, D. V., Dykens, E., Sparrow, S. S., Leckman, J. F., & Cohen, D. J. (1988). An evaluation of the Autism Behaviour Checklist. *Journal of Autism and Developmental Disorders, 18*(1), 81-97.

Volkmar, F. R., & Cohen, D. J. (1989). Disintegrative disorder or "late onset" autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 30*(5), 717-724.

Volkmar, F. R., Cohen, D. J., Hoshino, Y., Rende, R. D., & Paul, R. (1988). Phenomenology and classification of the childhood psychoses. *Psychological Medicine, 18*(1), 191-201.

Volkmar, F., Cook, E., Jr., Pomeroy, J., Realmuto, G., & Tanguay, P. (1999). Summary of the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Autism and other Pervasive Developmental Disorders. American Academy of Child and Adolescent Psychiatry. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*(12), 1611-1616.

Volkmar, F. R., Klin, A., Marans, W. D., & Cohen, D. J. (1997). Childhood Disintegrative Disorder In D. J. Cohen & F. R. Volkmar (Eds.), *Autism and pervasive developmental disorders* (2nd ed., pp. 47-59). New York Wiley.

Volkmar, F. R., Klin, A., Schultz, R., Bronen, R., Marans, W. D., Sparrow, S., & Cohen, D. J. (1996). Asperger's syndrome. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*(1), 118-123.

Volkmar, F., Klin, A., Schultz, R., Chawarska, K., & Jones, W. (2003). The social brain in autism. In M. Brune, H. Ribbert & W. Scheifenhoval (Eds.), *The Social Brain: Evolution and Pathology*. New York John Wiley & Sons.

Volkmar, F. R., Klin, A., Schultz, R. T., Rubin, E., & Bronen, R. (2000). Asperger's disorder. *The American Journal of Psychiatry, 157*(2), 262-267.

Volkmar, F. R., Klin, A., Siegel, B., Szatmari, P., Lord, C., Campbell, M., . . . et al. (1994). Field trial for autistic disorder in DSM-IV. *The American Journal of Psychiatry, 151*(9), 1361-1367.

Volkmar, F. R., Lord, C., Bailey, A., Schultz, R. T., & Klin, A. (2004). Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 45*(1), 135-170.

Volkmar, F. R., & Nelson, D. S. (1990). Seizure disorders in autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 29*(1), 127-129.

Volkmar, F. R., Steir, D. M., & Cohen, D. J. (1985). Age of Recognition of Pervasive Developmental Disorders. *The American Journal of Psychiatry, 142* (12), 1450-1452.

Wakefield, A. J. (1999). MMR vaccine and autism, *The Lancet, 354*, 950-951.

Walker, D. R., Thompson, A., Zwaigenbaum, L., Goldberg, J., Bryson, S. E., Mahoney, W. J., . . . Szatmari, P. (2004). Specifying PDD-NOS: a comparison of PDD-NOS, Asperger syndrome, and autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 43*(2), 172-180.

Waltz, C. F., Strickland, O. L., & Lenz, E. R. (2005). *Measurement in Nursing and Health Research* (3rd ed). New York Springer.

Wassink, T. H., Piven, J., & Patil, S. R. (2001). Chromosomal abnormalities in a clinic sample of individuals with autistic disorder. *Psychiatric Genetics, 11*(2), 57-63.

Webb, E., Morey, J., Thompsen, W., Butler, C., Barber, M., & Fraser, W. I. (2003). Prevalence of autistic spectrum disorder in children attending mainstream schools in a Welsh education authority. *Developmental Medicine and Child Neurology, 45*(6), 377-384.

Wechsler, D. (1981). Wechsler adult intelligence scale-revised. San Antonio, TX Psychological Corporation.

Wechsler, D. (1992). Wechsler Intelligence Scale for Children. London , UK The Psychological Corporation.

Weshler, D. (2002). *Weshler Preschool & Primary Scale of Intelligence* (3rd ed.): Pearson Assessments.

Weshler, D. (2003). *Weshler Intelligence Scales for Children* (4th ed.). San Antanio, TX: Psychological Corporation.

Weidmer-Mikhail, E., Sheldon, S., & Ghaziuddin, M. (1998). Chromosomes in autism and related pervasive developmental disorders: a cytogenetic study. *Journal of Intellectual Disability Research, 42 (Pt 1)*, 8-12.

Werner, E., & Dawson, G. (2005). Validation of the phenomenon of autistic regression using home videotapes. *Archives of General Psychiatry, 62*(8), 889-895.

Westibrot, D. M., & Godow, K. D. (2005). The presentation of anxiety in children with pervasive developmental disorders *Journal of Child and Adolescent Psychopharmacology, 15*, 477-496.

White, S. W., Ollendick, T., Scahill, L., Oswald, D., & Albano, A. M. (2009). Preliminary efficacy of a cognitive-behavioural treatment program for anxious youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(12), 1652-1662.

Wiggins, L. D., Baio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Development and Behavioural Paediatrics, 27*(2 Suppl), S79-87.

Wiggins, L. D., Bakeman, R., Adamson, L. B., & Robins, D. L. (2007). The utility of the social communication questionnaire in screening for autism in children referred for early intervention. *Focus on Autism and Other Developmental Disabilities, 22*(1), 33-38.

Williams, E., Thomas, K., Sidebotham, H., & Emond, A. (2008). Prevalence and characteristics of autistic spectrum disorders in the ALSPAC cohort. *Developmental Medicine and Child Neurology, 50*(9), 672-677.

Williams, J., Allison, C., Scott, F., Stott, C., Bolton, P., Baron-Cohen, S., & Brayne, C. (2006). The Childhood Asperger Syndrome Test (CAST): test-retest reliability. *Autism, 10*(4), 415-427.

Williams, J., & Brayne, C. (2006). Screening for autism spectrum disorders: what is the evidence? *Autism, 10*(1), 11-35.

Williams, J., Scott, F., Stott, C., Allison, C., Bolton, P., Baron-Cohen, S., & Brayne, C. (2005). The CAST (Childhood Asperger Syndrome Test): test accuracy. *Autism, 9*(1), 45-68.

Williamson, S. L., & Christodoulou, J. (2006). Rett syndrome: new clinical and molecular insights. *European Journal of Human Genetics, 14*(8), 896-903.

Wilson, J. M. G., & Jungner, G. (1968). Principals of Screening for Disease World Health Organisation.

Wing, J. K., Copper, J. E., & Sartorius, N. (1974). *Measurement and Classification of Psychiatric Symptoms,* Cambridge University Press.

Wing, L. (1981). Asperger's syndrome: a clinical account. *Psychological Medicine, 11*(1), 115-129.

Wing, L., & Attwood, A. J. (1987). Syndromes of Autism and Atypcial Development. . In D. J. Cohen & D. R.P (Eds.), *Handbook of Autism and Pervasive Developmental Disorders* (pp. 3-19). New York Wiley.

Wing, L. (2000). Past and future of research on Asperger syndrome. In A. Klin, F. Volkmar & S. Sparrow (Eds.), *Asperger syndrome* (pp. 418-432). New York Guildford.

Wing, L., & Gould, J. (1979). Severe impairments in social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*(1), 11-29.

Wing, L., Gould, J., & Gillberg, C. (2011). Autism spectrum disorders in the DSM-V: better or worse than the DSM-IV? *Research in Developmental Disabilities, 32*(2), 768-773.

Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry, and Allied Disciplines 43*(3), 307-325.

Witwer, A. N., & Lecavalier, L. (2008). Examining the validity of autism spectrum disorder subtypes. *Journal of Autism and Developmental Disorders, 38*(9), 1611-1624.

Wolff, S., & Barlow, A. (1979). Schizoid personality in childhood: a comparative study of schizoid, autistic and normal children. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 20*(1), 29-46.

Wolpert, C. M., Menold, M. M., Bass, M. P., Qumsiyeh, M. B., Donnelly, S. L., Ravan, S. A., . . . Pericak-Vance, M. A. (2000). Three probands with autistic disorder and isodicentric chromosome 15. *American Journal of Medical Genetics, 96*(3), 365-372.

Woodbury-Smith, M., Klin, A., & Volkmar, F. (2005). Asperger's syndrome: a comparison of clinical diagnoses and those made according to the ICD-10 and DSM-IV. *Journal of Autism and Developmental Disorders, 35*(2), 235-240.

Woodbury-Smith, M. R., & Volkmar, F. R. (2009). Asperger syndrome. *European Child & Adolescent Psychiatry, 18*(1), 2-11.

Woodcock, R. W., McGrew, K.S, Mather, N. (2001). *Woodcock - Johnson III Test of Cognitive Abilities* Itasca IL: Riverside Publishing.

World Health Organisation, W. (1992). The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines. Geneva World Health Organisation.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of autism in a US metropolitan area. *JAMA, 289*(1), 49-55.

Young, R. L., Brewer, N., & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism, 7*(2), 125-143.

Zweig, M. H., & Campbell, G. (1993). Receiver-operating characteristic (ROC) plots: a fundamental evaluation tool in clinical medicine. *Clinical Chemistry, 39*(4), 561-577.

Appendix A
Information Leaflet

Dublin City University

Autism Counts – calling all School Children

Autism Spectrum Disorder Research (ASD) Study 2010 - 2011

Autism Spectrum Disorder is a condition affecting the way in which children socialise, communicate and behave. We do not know how many children in Ireland are affected by this condition. The purpose of the research study is to find out how many children are affected. This information may lead to an improvement in services for children/families affected. The study is being conducted by researchers at **Dublin City University** and is being funded by **Irish Autism Action**. The school your child is attending has agreed to take part in the study. We are inviting every child in your school aged between 6-11 years of age to take part in the study. A study pack will be given to all children in the school in the coming days to be completed by parents/guardians. We would really appreciate your participation. If you have any questions about this study please feel free to contact Andrew Boilson at DCU on 01 7008527 andrew.boilson@dcu.ie or see our website www.autismcounts.eu.

Appendix B

Reminder Letter

DublinCityUniversity

Autism Counts – calling all School Children

Autism Spectrum Disorder Research (ASD) Study 2010 - 2011

Dear Parents / Guardians,

The DCU study team would greatly appreciate if parents / guardians who received an "Autism Counts" study pack would complete it and have it returned to the child's teacher as soon as possible.

If you are willing for your child to participate in the study please complete the study booklet, place it in the envelope provided (sealed) and return it to the child's teacher. Thank you for taking the time to do this.**All information provided will be treated in the strictest confidence.**

If you have any questions or need any assistance completing the study booklet please contact a member of the study team at the following number 01 7008527, email

andrew.boilson@dcu.ie or see our website www.autismcounts.eu.

Sincerely,

Andrew Boilson

Research Associate,

DCU, School of Nursing

DCU

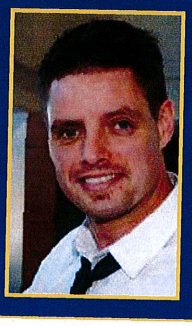
Appendix C

Study Booklet Envelope

Autism Counts

SURVEY PACK

2009 - 2011



Appendix D

STRICTLY CONFIDENTIAL

Dublin City University
Autism Counts
Autism Spectrum Disorder (ASD) Research Study 2010 – 2011

Consent form NS

Autism Spectrum Disorder is a condition affecting the way in which children socialise, communicate and behave. We do not know how many children in Ireland are affected by this condition. The purpose of this research study is to find out how many children are affected. This information may lead to an improvement in services for children/families affected. The study is being conducted by researchers at **Dublin City University** and is being funded by **Irish Autism Action**. The school your child is attending has agreed to take part in the study. All children aged between 6 and 11 years are invited to take part.

Please find enclosed in this study pack a consent form and a booklet containing a number of questionnaires, one of which is commonly used to screen children for Autism Spectrum Disorders. Children with high scores in the questionnaire will be invited to attend for further screening. If this happens you will be contacted by a member of the research team. This further screening can be done at the school your child is attending or at the family home. Children who are found to have high scores but are not diagnosed with Autism Spectrum Disorder on completion of assessments will be advised to follow up their results with their own GP. If your child has already had a psychological assessment in the school or elsewhere, we seek your permission to access these records.

Some children with scores in the normal range will be asked to complete a second questionnaire at a later stage. This is simply being done to compare the screening questionnaires with each other.

We are inviting parents / guardians of all children between 6 and 11 years to take part in the study. Your child must have been born between 1st January 1998 and 31st December 2003 to be eligible to take part.

If you have more than one child in the school aged between 6 and 11 years it is important to complete a booklet for each one of them. Thank you for taking the time to do this.

If your child is not in the age range please write not in the age range on the outside of the envelope and return it to the child's teacher.

If you agree to your child taking part in the study please sign the consent form and complete the booklet provided. Please seal the envelope to ensure confidentiality. The study pack should be returned to the child's teacher, which will be collected by the DCU research team.

Your child's participation in the study is completely voluntary. You may withdraw him/her from the study at any time. Your booklet has been assigned a unique code number. Only the research team and school principal will know your child's identity. Once the questionnaires are returned to the study team the data will be scanned and stored without your child's name on it.

If you have any questions about this study or need help answering the questions please feel free to contact Andrew Boilson at DCU on 01 7008527, by email to andrew.boilson@dcu.ie or see our website www.autismcounts.eu

I have read and understood the information in this form. I consent to my child taking part in this research project.

Child's Name in Block Capitals: _____

Parent's/Guardian's Signature: _____

Contact Number: _____ Today's Date: ___/___/___

We are planning further studies which will explore the causes of Autism/Autism Spectrum Disorder and we seek your permission to contact you at a later time regarding these studies. Do you consent to be contacted at a future date regarding these research studies?

Yes ☐ No ☐

Section 1
The Study Child

For the purpose of this study we will refer to your child as the "Study Child". Please complete the following on their behalf. These questions should be completed by the person who has provided most care for the Study Child since birth.

Please mark ☒ in the appropriate box using a biro or pen.

Q1 Are you the person who has provided most care for the Study Child since birth? Yes ☐ No ☐

Q2 Which of the following best describes your relationship with the Study Child?

Biological Mother	☐	Foster Mother	☐
Biological Father	☐	Foster Father	☐
Biological Mother and Father	☐	Foster Mother and Foster Father	☐
Adoptive Mother	☐	Grandmother	☐
Adoptive Father	☐	Grandfather	☐
Adoptive Mother and Father	☐	Grandmother and Grandfather	☐
Step-Mother	☐	Aunt	☐
Step-Father	☐	Uncle	☐
Step Mother and Father	☐	Aunt & Uncle	☐

Other relative(s) / guardian(s), please state_____

Q3 Who does the Study Child normally live with?

Biological Mother	☐	Foster Mother	☐
Biological Father	☐	Foster Father	☐
Adoptive Mother	☐	Grandmother	☐
Adoptive Father	☐	Grandfather	☐
Step-Mother	☐	Aunt	☐
Step-Father	☐	Uncle	☐

Other relationship, please state:_____

Q4 Study Child's Date of Birth _____/ _____ / _____ DD / MM / YY

Q5 Study Child's Gender Male ☐ Female ☐

Q6 Where does the Study Child currently live?

_____

_____

County _____

PLEASE PROVIDE YOUR POSTAL ADDRESS WITHOUT THE STREET NUMBER OR HOUSE NAME.
EXAMPLE:
Trees Road,
Stillorgan,
Co Dublin.

Please mark ☒ in the appropriate box using a biro or pen.

Q7 Was the Study Child born in Ireland? Yes ☐ No ☐

If you answered yes to Q7 please proceed to Q10, if you answered no proceed to Q8.

Q8 In which country was he / she born? Please state_____ Don't know ☐

Q9 How long ago did the Study Child first come to live in Ireland?

Within the last year ☐ 1-5 years ago ☐ 6-10 years ago ☐ Over 10 years ago ☐

Don't Know ☐

Q10 Do you think the Study Child has any Learning, Communication or Co-ordination difficulties? Yes ☐ No ☐

If you answered yes to Q10 proceed to Q11, if you answered no proceed to Q17.

Q11 What is the nature of the difficulty or disorder? (Tick all that apply)

Dyslexia (incl. Dysgraphia, Dyscalculia)	☐	Speech & Language Difficulty	☐
ADHD (Attention Deficit Hyperactivity Disorder)	☐	Dyspraxia	☐
Autism Spectrum Disorder	☐	Slow progress (reasons unclear)	☐
Asperger Syndrome	☐	Other	☐

Other (Please specify) _____

Q12 Was the Study Child diagnosed by a professional? Yes ☐ No ☐ Awaiting Consultation ☐

If you answered yes to Q12 proceed to Q13, if you answered no or awaiting consultation proceed to Q15.

Q13 Where was the Study Child diagnosed? (Name/Address of Psychiatrist/Psychologist/Doctor etc.)

Name of Psychiatrist/Psychologist_____

Address_____

	Less than 6 months of age	6–12 months of age	1-2 years of age	Longer than 2 years of age
Q14 How long ago was the Study Child diagnosed?	☐	☐	☐	☐

Date of Diagnosis: Year _____ Month _____

Q15 When do you think the Study Child first showed any problems or difficulties in development or behaviour?

Before 1st birthday	☐	Before 2nd birthday	☐
Before 3rd birthday	☐	Before 4th birthday	☐
Before 5th birthday	☐	Before 6th birthday	☐

Other birthday, please state: _____

Please mark ☒ in the appropriate box using a biro or pen.

Q16 What was it that gave you concerns at the time?

Describe the behaviour displayed by the Study Child at the time.

_____

_____

_____

_____

_____

Q17 Does the Study Child receive any of the support services listed below inside school or outside of school?

Yes ☐ No ☐

If you answered <u>yes</u> to Q17 please tick all that apply. If you answered <u>no</u> proceed to Q19.

In school

Special Needs/Resource Teaching hours	
Special Needs Assistant	
Speech and Language Therapy	
Occupational Therapy	
Physiotherapy	
School Nurse	
Psychologist	
Learning Support Teacher	
Other (please specify)	

Outside school

Speech and Language Therapy	
Occupational Therapy	
Physiotherapy	
Psychologist	
Psychiatrist	
Other (please specify)	

Q18 Where is the Study Child receiving these support services?

(Please provide the name and address of the school/centre)

Name of School/Centre _____

Address _____

_____

Section 2
The Study Child's Pregnancy & Birth

Q19 Was the Study Child a single birth, twin, triplet etc? Single child ☐ Twin ☐ Triplet ☐ Other (Write number in box) ☐

Q20 Did the biological mother take folic acid supplements before her pregnancy with the Study Child? Yes ☐ No ☐

If you answered yes to Q20 proceed to Q21, if no proceed to Q23.

Q21 If yes, how long did she take folic acid supplements for prior to becoming pregnant with the Study Child?

Weeks _____ Months _____ Years _____

Q22 If yes, please state the dose of folic acid supplements that she took?

400 micrograms ☐

4 mgs ☐

Unknown amount ☐

Other amount (please state) _____

Q23 How much did the Study Child weigh at birth?

Pounds ☐ Ounces ☐

Kilos ☐ Grams ☐ Don't know ☐

Please record the Study Child's weight at birth in Pounds & Ounces or Kilos & Grams.

Q24 Was the Study Child born?

Early (< 37 wks) ☐

At term (On Due Date) (37 - 42 wks) ☐

Late (> 42 wks) ☐

Don't know ☐

Q25 How many weeks of pregnancy was the Study Child born at?

Weeks _____ Don't know ☐

Q26 What was the mode of delivery?

A. Normal birth (vaginal delivery) ☐

B. Suction assisted birth ☐

C. Forceps assisted birth ☐

D. Elective Caesarean ☐

E. Emergency Caesarean ☐

F. Other ☐

G. Don't Know ☐

Other, please specify_____

Please mark ☒ in the appropriate box using a biro or pen.

Q27 Did the Study Child have to go to a Neonatal Intensive Care Unit or Special Care Nursery after he/she was born?

Yes	No	Don't know
☐	☐	☐

Q28 How old was the Study Child when he/she came home from hospital (or special care)?

Days _____ Weeks _____ Months _____

Please mark ☒ in the appropriate box using a biro or pen.

Section 3
The Study Child's Post Natal Care

Q29 Did the biological mother suffer from any of the following during or after pregnancy with the Study Child:

	During Pregnancy			Up to 12 months After Pregnancy		
	Yes	No	Don't know	Yes	No	Don't know
Hypertension (high blood pressure)						
Pre-eclampsia						
Diabetes						
Post-natal depression						

Q30 Was the Study Child ever breastfed (even just in the few hours after birth)?

Yes ☐ No ☐ Don't know ☐

If you answered <u>yes</u> to Q30 proceed to Q31, if you answered <u>no</u> or <u>don't know</u> proceed to Q33.

Q31 How old was the Study Child when he /she completely stopped being breastfed? (including expressed milk)

PLEASE WRITE THE STUDY CHILD'S AGE IN THE RELEVANT BOX

Days ☐ Weeks ☐ Months ☐ Years ☐ Don't know ☐

Q32 How old was the Study Child when he / she first had any milk or drinks other than breast milk? (not including water)

PLEASE WRITE THE STUDY CHILD'S AGE IN THE RELEVANT BOX

Days ☐ Weeks ☐ Months ☐ Years ☐ Don't know ☐

Q33 How old was the Study Child when he / she was first given solids? (including baby rice and cereals)

PLEASE WRITE THE STUDY CHILD'S AGE IN THE RELEVANT BOX

Days ☐ Weeks ☐ Months ☐ Years ☐ Don't know ☐

Please mark ☒ in the appropriate box using a biro or pen.

Q34 Has a general practitioner (GP) or public health nurse ever diagnosed the Study Child with any of the following:

Health Problems	Yes/No	Diagnosed by: Name / Address of Doctor / Public Health Nurse	Date of Diagnosis: (Approximate)
Hearing			
Sight (Vision)			
Asthma			
Eczema			
Migraine			
Ear infections			
Food or other allergies			
Other illnesses			
Physical disability			

If you stated the Study Child has been diagnosed with other illnesses or a physical disability in Q34 proceed to Q35.
If you answered no proceed to Section 4 - Social Communication Questionnaire on page 8.
Please read the directions before answering the questions in this section.

Q35 Please provide details of other illnesses or physical disabilities the Study Child was diagnosed with by a general practitioner (GP) or nurse.

Section 4
Social Communication Questionnaire (SCQ)

Directions

Thank you for taking the time to complete this questionnaire. Please answer each question by answering *yes* or *no*. A few questions ask about several related types of behaviour; please mark **X** in the appropriate box if *any* of these behaviours have ever been present. Although you may be uncertain about whether some behaviours were ever present or not, please answer *yes* or *no* to every question on the basis of what you think.

Please mark ☒ in the appropriate box using a biro or pen to answer *yes* or *no* to each question.

Q36. Is she/he now able to talk using short phrases or sentences? Yes ☐ No ☐
(If *no*, skip to question 43) .....

Q37. Can you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said? ..... Yes ☐ No ☐

Q38. Has she/he ever used odd phrases or said the same thing over and over in almost exactly the same way (either phrases that she/he has heard other people use or ones that she/he has made up)? ..... Yes ☐ No ☐

Q39. Has she/he ever used socially inappropriate questions or statements? For example, has she/he ever regularly asked personal questions or made personal comments at awkward times? ..... Yes ☐ No ☐

Q40. Has she/he ever got her/his pronouns mixed up (e.g., saying *you* or *she/he* for *I*)? ..... Yes ☐ No ☐

Q41. Has she/he ever used words that she/he seemed to have invented or made up her/himself; put things in odd, indirect ways; or used metaphorical ways of saying things (e.g., saying *hot rain* for *steam*)? ..... Yes ☐ No ☐

Q42. Has she/he ever said the same thing over and over in exactly the same way or insisted that you say the same thing over and over again? ..... Yes ☐ No ☐

Q43. Has she/he ever had things that she/he seemed to have to do in a very particular way or order or rituals that she/he insisted that you go through? ..... Yes ☐ No ☐

Q44. Has her/his facial expression usually seemed appropriate to the particular situation, as far as you could tell? ..... Yes ☐ No ☐

Q45. Has she/he ever used your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger, putting your hand on a doorknob to get you to open the door)?.... Yes ☐ No ☐

Please mark ☒ in the appropriate box using a biro or pen to answer *yes* or *no* to each question.

Q46. Has she/he ever had any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)? ..... Yes ☐ No ☐

Q47. Has she/he ever seemed to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than using the object as it was intended? ..... Yes ☐ No ☐

Q48. Has she/he ever had any special interests that were *unusual* in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains, dinosaurs)? ..... Yes ☐ No ☐

Q49. Has she/he ever seemed to be *unusually* interested in the sight, feel, sound, taste, or smell of things or people? ..... Yes ☐ No ☐

Q50. Has she/he ever had any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes? ..... Yes ☐ No ☐

Q51. Has she/he ever had any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down? ..... Yes ☐ No ☐

Q52. Has she/he ever injured her/himself deliberately, such as by biting her/his arm or banging her/his head? ..... Yes ☐ No ☐

Q53. Has she/he ever had any objects (*other* than a soft toy or comfort blanket) that she/he *had* to carry around? ..... Yes ☐ No ☐

Q54. Does she/he have any particular friends or a best friend? ..... Yes ☐ No ☐

For the following behaviours, please focus on the time period between the child's fourth and fifth birthdays. You may find it easier to remember how things were at that time by focusing on key events, such as starting school, moving house, Christmastime, or other specific events that are particularly memorable for you as a family.

Please mark ☒ in the appropriate box using a biro or pen to answer *yes* or *no* to each question.

Q55. When she/he was 4 to 5, did she/he ever talk with you just to be friendly (rather than to get something)? ..... Yes ☐ No ☐

Q56. When she/he was 4 to 5, did she/he ever *spontaneously* copy you (or other people) or what you were doing (such as vacuuming, gardening, or mending things)? ..... Yes ☐ No ☐

Q57. When she/he was 4 to 5, did she/he ever spontaneously point at things around her/him just to to show you things (not because she/he wanted them)? ..... Yes ☐ No ☐

Q58. When she/he was 4 to 5, did she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wanted? ..... Yes ☐ No ☐

Q59. When she/he was 4 to 5, did she/he nod her/his head to mean *yes*? ..... Yes ☐ No ☐

Q60. When she/he was 4 to 5, did she/he shake her/his head to mean *no*? ..... Yes ☐ No ☐

Q61. When she/he was 4 to 5, did she/he usually look at you directly in the face when doing things with you or talking with you? ..... Yes ☐ No ☐

Q62. When she/he was 4 to 5, did she/he smile back if someone smiled at her/him? ..... Yes ☐ No ☐

Q63. When she/he was 4 to 5, did she/he ever show you things that interested her/him to engage your attention? ..... Yes ☐ No ☐

Q64. When she/he was 4 to 5, did she/he ever offer to share things other than food with you? ..... Yes ☐ No ☐

Q65. When she/he was 4 to 5, did she/he ever seem to want you to join in her/his enjoyment of something? ..... Yes ☐ No ☐

Please mark ☒ in the appropriate box using a biro or pen to answer *yes* or *no* to each question.

Q66. When she/he was 4 to 5, did she/he ever try to comfort you if you were sad or hurt? ..... Yes ☐ No ☐

Q67. When she/he was 4 to 5, when she/he wanted something or wanted help, did she/he look at you and use gestures with sounds or words to get your attention? ..... Yes ☐ No ☐

Q68. When she/he was 4 to 5, did she/he show a normal range of facial expressions? ..... Yes ☐ No ☐

Q69. When she/he was 4 to 5, did she/he ever spontaneously join in and try to copy the actions in social games, such as *The Mulberry Bush* or *London Bridge Is Falling Down*? ..... Yes ☐ No ☐

Q70. When she/he was 4 to 5, did she/he play any pretend or make-believe games? ..... Yes ☐ No ☐

Q71. When she/he was 4 to 5, did she/he seem interested in other children of approximately the same age whom she/he did not know? ..... Yes ☐ No ☐

Q72. When she/he was 4 to 5, did she/he respond positively when another child approached her/him? Yes ☐ No ☐

Q73. When she/he was 4 to 5, if you came into a room and started talking to her/him without calling her/his name, did she/he usually look up and pay attention to you? ..... Yes ☐ No ☐

Q74. When she/he was 4 to 5, did she/he ever play imaginative games with another child in such a way that you could tell that they each understood what the other was pretending? ..... Yes ☐ No ☐

Q75. When she/he was 4 to 5, did she/he play cooperatively in games that required joining in with a group of other children, such as hide-and-seek or ball games? ..... Yes ☐ No ☐

Please mark ☒ in the appropriate box using a biro or pen.

Section 5
Study Child's Brothers & Sisters

Q76. For each child in the family can you provide the following information in the table below.

The table below does not have to be completed for the Study Child as this information has been recorded elsewhere is the questionnaire. If the Study Child is an only child proceed to Q77.

Birth Order (If you have more than 5 children, please add the information below)	Gender	Date of Birth	Has the child ever received education support at school or elsewhere?	Has the child ever received a diagnosis of Autism Spectrum Disorder?
1st born child	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
2nd born child	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
3rd born child	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
4th born child	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
5th born child	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐
	M ☐ F ☐	day_____/month______/year_____	Yes ☐ No ☐	Yes ☐ No ☐

Please mark ☒ in the appropriate box using a biro or pen.

Q77 Do the Study Child's siblings receive support services inside or outside of school?

Yes ☐ No ☐

If you answered yes to Q77 please tick *all* that apply, if you answered no proceed to Q78.

In school		**Outside school**	
Special Needs/Resource Teaching hours	☐	Speech and Language Therapy	☐
Special Needs Assistant	☐	Occupational Therapy	☐
Speech and Language Therapy	☐	Physiotherapy	☐
Occupational Therapy	☐	Psychologist	☐
Physiotherapy	☐	Psychiatrist	☐
School Nurse	☐	Other (please specify)	☐
Psychologist	☐		
Learning Support Teacher	☐		
Other (please specify)	☐		

Section 6
You and Your Household

Q78 What is your current marital status?

- Single (never married) ☐
- Co-habiting ☐
- Married ☐
- Separated ☐
- Divorced ☐
- Widowed ☐

Q79 Do you live in a:

House ☐ Apartment / Flat / Bedsit ☐ Other (specify)_____

Q80 Which best describes your occupancy of the accommodation?

- Owner occupied (with or without mortgage) ☐
- Being purchased from Local Authority under a Tenant Purchase Scheme ☐
- Rented from a Local Authority ☐
- Rented from a Voluntary Body ☐
- Rented from a Private Landlord ☐
- Living with and paying rent to your (or your partner's) parent(s) ☐
- Occupied free of rent with your (or your partner's) parent(s) ☐
- Occupied free of rent from your or your partner's job ☐

Please mark ☒ in the appropriate box using a biro or pen.

The questions in the table below, Q81 to Q85, should be completed for both the Study Child's mother and father.

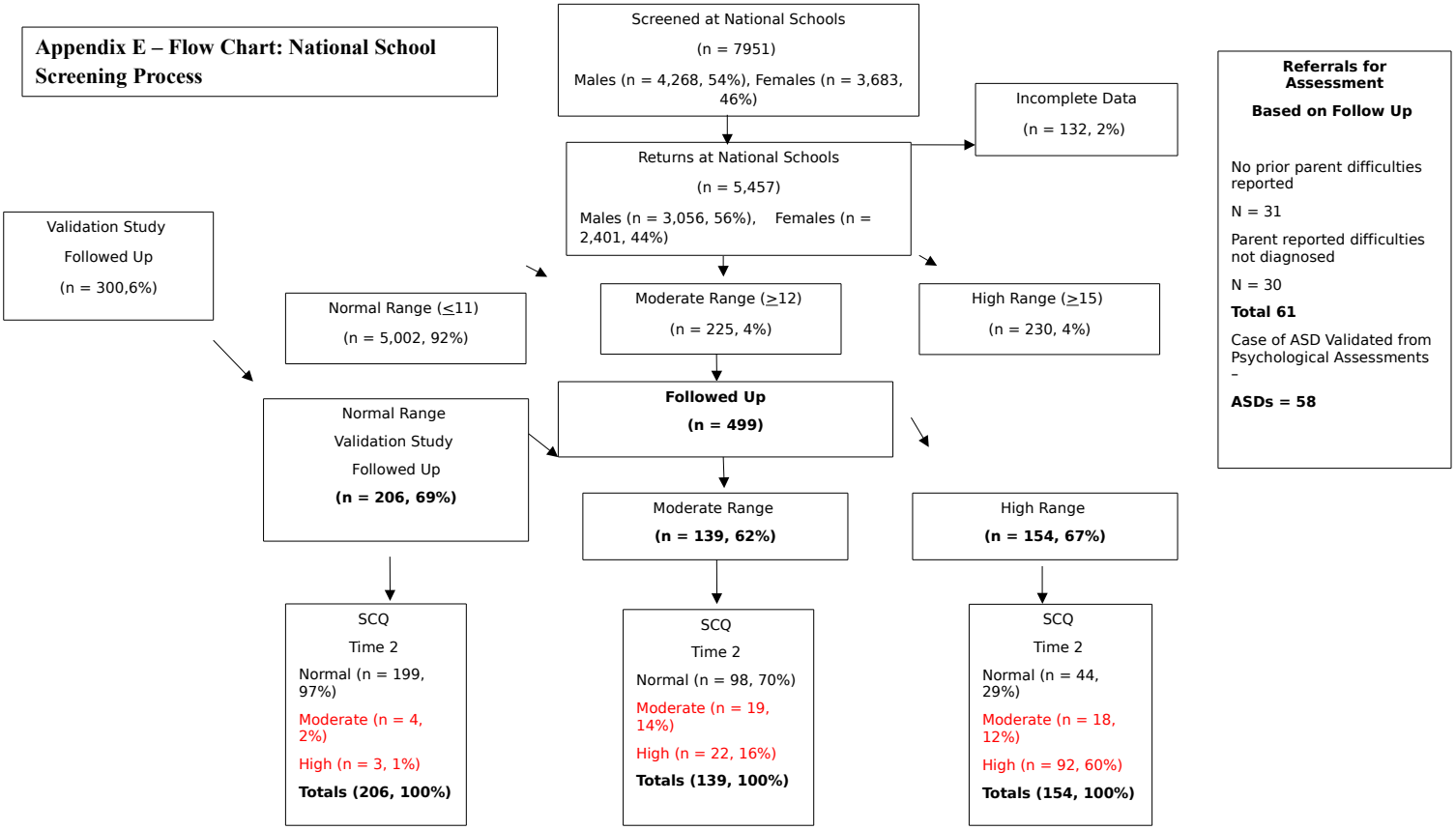
	Please complete this column with information on the Study Child's Mother	**Please complete this column with information on the Study Child's Father**
Q81 Which of these BEST describes the mother's / father's current situation in regard to work? ***If you selected for mother / father:*** ***Employee, Self employed, Farmer proceed to Q82*** ***If unemployed proceed to Q85*** ***Any other category proceed to Q86***	Employee (incl. apprenticeship or Community Employment) ☐ Self employed outside farming ☐ Farmer ☐ Student full time ☐ On State training scheme (FAS, Fáilte Ireland etc) ☐ Unemployed, actively looking for a job ☐ Long-term sickness or disability ☐ Home duties / looking after home or family ☐ Retired ☐ Other, please specify _____	Employee (incl. apprenticeship or Community Employment) ☐ Self employed outside farming ☐ Farmer ☐ Student full time ☐ On State training scheme (FAS, Fáilte Ireland etc) ☐ Unemployed, actively looking for a job ☐ Long-term sickness or disability ☐ Home duties / looking after home or family ☐ Retired ☐ Other, please specify _____
Q82 How many hours a week does the mother / father work?	Hours per week _____	Hours per week _____
Q83 What is the mother's / father's occupation?	Please state _____	Please state _____
Q84 Does the mother / father supervise, manage or employ any personnel in their job? ***If you answered yes or no to Q84 proceed to Q86***	Yes ☐ No ☐ If yes, how many? _____	Yes ☐ No ☐ If yes, how many? _____
Q85 If currently unemployed what was the mother's / father's usual situation with regards to work?	Employee (incl. apprenticeship or Community Employment) ☐ Self employed outside farming ☐ Farmer ☐ Other, please specify _____ Usual Occupation _____ NA ☐	Employee (incl. apprenticeship or Community Employment) ☐ Self employed outside farming ☐ Farmer ☐ Other, please specify _____ Usual Occupation _____ NA ☐

Please mark ☒ in the appropriate box using a biro or pen.

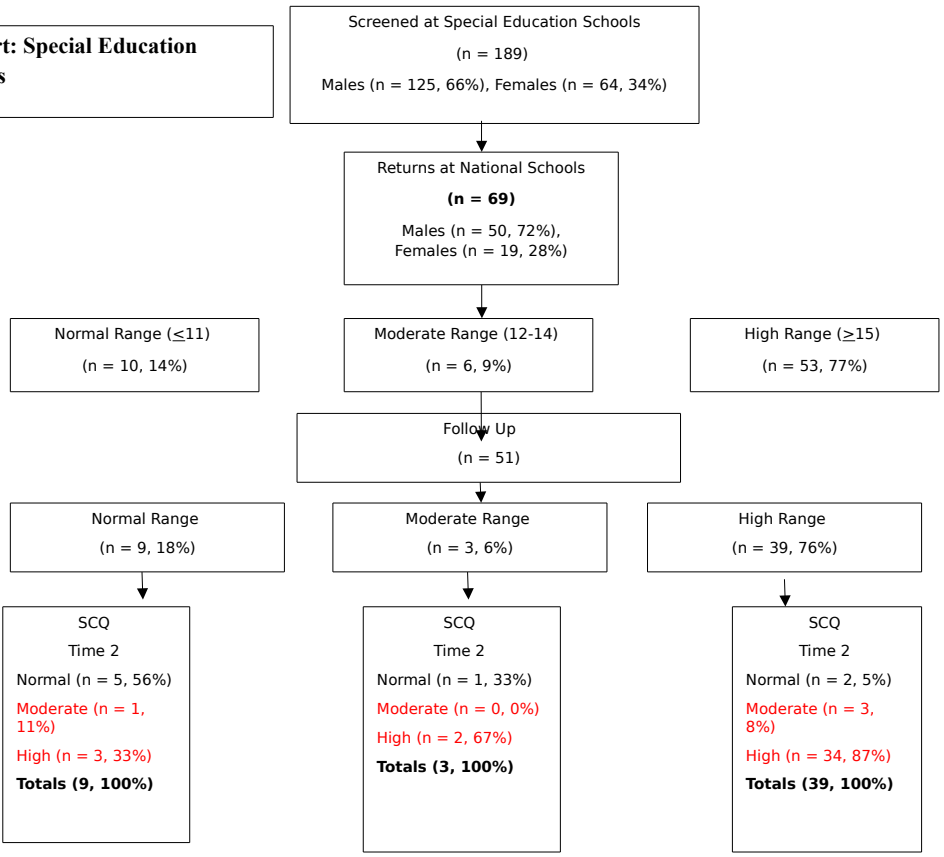
The questions in the table below, Q86 to Q93, should be completed for <u>both</u> the Study Child's mother and father.

	Please complete this column with information on the Study Child's <u>Mother</u>	**Please complete this column with information on the Study Child's <u>Father</u>**
Q86 What is the highest level of education the mother / father has completed to date?	Primary or less ☐ Intermediate/ Junior/ Group Certificate or equivalent ☐ Leaving Certificate or equivalent ☐ Diploma / Certificate ☐ Primary degree ☐ Postgraduate/ Higher degree ☐	Primary or less ☐ Intermediate/ Junior/ Group Certificate or equivalent ☐ Leaving Certificate or equivalent ☐ Diploma / Certificate ☐ Primary degree ☐ Postgraduate/ Higher degree ☐
Q87 Is English the mother's / father's native language? **If you answered <u>yes</u> proceed to Q89, if <u>no</u> proceed to Q88**	Yes ☐ No ☐	Yes ☐ No ☐
Q88 What is the mother's / father's native language?		
Q89 Were the mother / father born in Ireland? **If you answered <u>yes</u> proceed to Q92, if <u>no</u> proceed to Q90**	Yes ☐ No ☐ Don't know ☐	Yes ☐ No ☐ Don't know ☐
Q90 In which country were the mother / father born?	Please state _____ Don't know ☐	Please state _____ Don't know ☐
Q91 How long ago did the mother / father first come to live in Ireland?	Within the last year ☐ 1-5 years ago ☐ 6-10 years ago ☐ 11-20 years ago ☐ More than 20 years ago ☐ Don't know ☐	Within the last year ☐ 1-5 years ago ☐ 6-10 years ago ☐ 11-20 years ago ☐ More than 20 years ago ☐ Don't know ☐
Q92 What is the mother's / father's ethnic or cultural background?	Irish ☐ Irish Traveller ☐ Any other white background ☐ African ☐ Any other black background ☐ Chinese ☐ Any other Asian background ☐ Other– incl. mixed background (specify) ☐ _____	Irish ☐ Irish Traveller ☐ Any other white background ☐ African ☐ Any other black background ☐ Chinese ☐ Any other Asian background ☐ Other– incl. mixed background (specify) ☐ _____
Q93 What is the mother's / father's Date of Birth	_____/ _____ / _____DD / MM / YY	_____/ _____ / _____DD / MM / YY

Appendix E – Flow Chart: National School Screening Process



Appendix F – Flow Chart: Special Education School Screening Process



Parent Reported Diagnosis –

ASDs	n = 36	52%
Unspecified	n = 9	13%
Down's syndrome		n = 8 12%
Speech & Language		n = 5 7%
Genetic Disorders		n = 5 7%
Cerebral Palsy	n = 3	4%
ID (Mod / Severe)		n = 3 4%
Totals	**69**	**100%**

Case of ASD Validated from Psychological Assessments –

ASDs = 36

Appendix G

Oral & Poster Presentations

Boilson A, Hourican S, McVeigh T, Staines A, Sweeney M.R.
The Social Communication Questionnaire (SCQ) test – retest reliability in an epidemiological sample of national school children. Poster presentation, 4th World Congress on ADHD, Milan, Italy, 6th – 9th June, 2013.

Boilson A, Staines A, Sweeney M.R.
The Social Communication Questionnaire (SCQ) discriminant validity in an epidemiological sample of national school children. Poster presentation, 4th World Congress on ADHD, Milan, Italy, 6th – 9th June, 2013.

Boilson A, Ramirez A, Posada M, Staines A, Sweeney M.R.
Development and Implementation of a European protocol for Autism Spectrum Disorder Prevalence (EPAP). Poster presentation, 4th World Congress on ADHD, Milan, Italy, 6th – 9th June, 2013.

Boilson A, Staines A, Sweeney M.R.
The Social Communication Questionnaire (SCQ) Distribution of scores by gender in an epidemiological sample of national school children. Poster presentation, 4th World Congress on ADHD, Milan, Italy, 6th – 9th June, 2013.

Boilson A, Staines A, Sweeney M.R.
Implementation of a European protocol for autism spectrum disorder prevalence. Poster presentation, 4th World Congress on ADHD, Milan, Italy, 6th – 9th June, 2013.

Boilson A, Staines A, Ramirez A, Sweeney M.R. Implementation of A European Protocol for Autism Prevalence. *Poster presentation, International Meeting for Autism Research (IMFAR), Donostia, San Sebastian, Spain, June 2-4th 2012*

Boilson A, Ramirez A, Posada M, Staines A, Sweeney MR. Development and Implementation of a European protocol for Autism Spectrum Disorder Prevalence (EPAP). *Poster presentation, European Child Health Conference, School of Nursing and Health Sciences, School of Nursing & Human Sciences, May 30th – 31st.*

Boilson A, Staines S, Sweeney MR, Ramirez R. Irish Autism Prevalence Study, Presentation of provisional results. Workshop on Epidemiology of ASDs. *Workshop, Irish Centre for Autism and Neuro-developmental Research Autism Spectrum Disorders: from Clinical Practice to Educational Provision, National University of Ireland, Galway, January 12 - 13, 2012*

Boilson A, Staines S, Sweeney MR: Irish Autism Prevalence Study methodology and result of a pilot study. *Oral presentation, Autism 2010 European Autism Conference*, *November 29th 2011.*