Second Level Education and Autism Spectrum Disorder: An Exploration of Peer, Parent and Teacher Experiences

By

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Trinity College Dublin
In fulfilment of the requirement of the Degree of Doctor of Philosophy

June 2018
I declare that this thesis has not been submitted as an exercise for a degree at this or any other University and it is entirely my own work.

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Acknowledgement

With gratitude to the parents, teachers and young people who participated in the studies. Thank you for sharing your time, experience and knowledge.

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Abstract

Adolescents with Autism Spectrum Disorder (ASD) are extensively reported to find the experience of secondary school challenging. Few studies have informed on this in detail, particularly considering social and behavioural factors. With reported poor post-secondary school outcomes and a recognition that adolescents with ASD experience high levels of anxiety and depression, this body of research aimed to examine this time in the life of the student with ASD. It aimed to specifically address perspectives of parents, teachers and peers in the secondary school setting. In order to achieve this, the current programme of research consists of four studies. The first study qualitatively examined parent perspectives on the transition and commencement of secondary school for their child with ASD. Eight parents were interviewed in depth. Thematic analysis indicated themes relating to, the transition process and its context; the importance of communication for a successful transition; the challenges of social participation for their child; how the individuality of their child and their ASD created specific issues; and the many factors for attainment in secondary school which are inextricably linked to unlocking the child’s potential. Overall the findings emphasised practical strategies for other parents based on their experience and a desire for their child to settle and attain in secondary school. The second study was a cross-sectional survey design with 105 participants representing students with ASD in Irish secondary schools. Parents and teachers reported on within student and school factors, including measures of positive social and problem behaviour in school. Descriptive analyses showed that 87.5% agreed or strongly agreed that school was challenging. Teachers reported being familiar with ASD, but less so with the principles of Applied Behaviour Analysis (ABA). High levels of anxiety were observed by teachers. Higher anxiety was found to relate to those who got on least well with others, and there was higher anxiety reported for students integrated into the mainstream than those in fulltime special classes. Regression analysis showed a relationship between social confidence, mainstream integration and adaptive social behaviour. No other relationships were found between school and student factors and social and problem behaviours. The study confirms that secondary school is a challenge for Irish students with ASD, that anxiety is frequently observed and it also appears to play a role in social experiences. The final two studies examined peers without ASD as a vital component of the social experience of secondary school for those with ASD. A representative sample (N=72) of Transition Year (TY) students completed self-report measures of knowledge, attitude, behavioural intentions and concepts related to ASD within a neurodiversity framework. Results revealed a wide range of knowledge, attitudes and intentional behaviours. Previous experience of ASD was predictive of higher levels of knowledge. Being female also predicted higher intentional behaviours. Students were not aware of neurodiversity but expressed attitudes in line with its concept. Reviews of interventions to change knowledge, attitude and intentional behaviour demonstrated weak evidence and a small research base, with some evidence that multi-component and contact interventions had the greatest impact. An intervention (Project ALLY- Autism and Lasting Links for Youth) was subsequently devised. All 72 TY students in the previous study were allocated to either the intervention or a control condition. The intervention showed a large effect for general social and academic intentional behaviours, and a medium effect for active recreation intentional behaviours and societal attitudes. There was a small effect for the standardised measure of knowledge, but a very large effect for knowledge specific to the intervention content. Feedback was positive from all students in the intervention condition. The findings from this body of research provide useful insights into perspectives on the secondary school experience for students with ASD. It is recommended that Project ALLY be further developed and investigated as a potential evidence-based intervention in secondary schools. Findings from all of the studies can be utilised for the development of services and support for students with ASD in second level education within an Irish context.
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Publications & Conference Presentations

Detailed below are works, from this thesis, that have been published or have been presented at conferences.

**Publication:**


**Conference Poster:**


**Submitted Publication:**

1 Chapter One: Overview of Thesis

1.1 Introduction

This chapter introduces the body of research presented in this thesis. It provides an overview of the current status of research literature in the field, outlines the general aims of the studies and summarises the chapters to follow.

1.2 Current Status of the Research Literature

The outcomes of secondary school for students with Autism Spectrum Disorder (ASD) have been internationally reported to reflect poorly on their educational and personal gains in secondary school (Dillenburger, Jordan, & McKerr, 2016; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). The secondary school environment and the transition to it, is viewed as a challenging adjustment for students with ASD (Hebron, 2017b; Hedges et al., 2014; Makin, Hill, & Pellicano, 2017). An increase in the pace of learning, moving from class to class and the overwhelming sensory environment are eluded to as complex challenges for those with ASD (McGillicuddy & O'Donnell, 2014). Students are managed within this system as opposed to addressing changes which may support greater inclusivity (McGillicuddy & O'Donnell, 2014). Students with ASD report feeling overwhelmed and at odds with the chaotic and busy environment (Saggers, 2015). While teachers report observing that unusual or unfamiliar behaviours of the students with ASD can “annoy” other students and are often poorly understood (Hedges et al., 2014; McGillicuddy & O'Donnell, 2014).

It is the social environment of secondary school which appears to be the greatest challenge to students with ASD, with the core difficulties of communication and social
skills putting students at risk of social isolation (Humphrey & Symes, 2010a).
Adolescence also brings its own issues to those with ASD including reported increase in anxiety and depression, and related behavioural and emotional difficulties (Hebron & Humphrey, 2014b; Schall & McDonough, 2010). Peer relationships have been identified as one of the most important features of adolescence, yet for students with ASD these are often difficult to establish or sometimes non-existent (Mendelson, Gates, & Lerner, 2016). Inclusive school policy has brought about physical proximity with peers but does not seem to have improved peer contact (Carter, Asmus, et al., 2016; Carter, Gustafson, et al., 2016). Students without ASD tend not to initiate interactions, feel awkward around peers with ASD and potentially attribute negative labels to those with ASD out of misinformation and negative attitudes (Campbell & Barger, 2014; Fondelli & Rober, 2016). There is a real identified need to examine the secondary school experience for students with ASD, particularly from a social and behavioural perspective so as to contribute to improvements in social support, inclusion experiences and quality of life (Hedges et al., 2014).

1.3 Overview of Chapters
This thesis is comprised of thirteen chapters representing four empirical studies and the related literature. Chapter 2 and 3 provide a context for the current programme of research by introducing ASD and the Irish educational context, with a particular emphasis on ASD during adolescence and the secondary school system. Chapters 4 to 7 provide a review of the literature from the perspective of the participants in the research studies and as the major stakeholders within the secondary school experience. These chapters represent reviews of the literature relating to parents, students with ASD, teachers / school personnel and students without ASD within the context of secondary
schools. Subsequent chapters report on the empirical studies. The first in Chapter 8 is a qualitative study and aimed to frame the context from a parental perspective. The second empirical study is reported in Chapter 9 and attempts to examine the secondary school experience from a number of within student and school factors, and to examine social and problem behaviours that students with ASD may be presenting with in secondary school. Chapters 10, 11 and 12 drill down into the social context and examine peers’ knowledge, attitude and intentional behaviours about and towards those with ASD, including concepts relating to neurodiversity. This includes a study of students without ASD, a thorough review of the evidence base, and finally a study reporting on the inception and evaluation of a programme to effect peers’ knowledge, attitude and intentional behaviours about and towards those with ASD, including concepts relating to neurodiversity in Irish secondary schools.

The empirical studies represent both qualitative and quantitative methodologies. Each study is distinct from the next, but all with the aim of increasing an understanding of the school experience of students with ASD. In line with this, results from each study are presented and discussed separately. Chapter 13 provides conclusions and aims to synthesise general findings, limitations and future directions.

1.4 Aims

Overall the body of research presented in this thesis aims to enhance general understanding of the secondary school experience for students with ASD in Ireland, with a focus on parents, teachers and to the greatest extent peers. Several studies were undertaken within the framework of this general aim. Collectively the research aims are summarised as follows:
Parental perspective on the transition to secondary school (Chapter 8) – This study aimed to explore the transition to secondary school and the proceeding period for students with ASD from the perspective of their parents.

Factors in the experience of secondary school (Chapter 9) - This study aimed to report on the secondary school factors, experience and participation for a representative sample of 105 students with ASD who attended mainstream secondary school in Ireland.

Peer knowledge and attitude (Chapter 10) - The aim of this study was to document and describe fourth year secondary school students’ knowledge of ASD, attitude and intentional behaviour toward ASD and their conceptions of neurodiversity. It also aimed to investigate factors relating to gender and previous experience of ASD as potential predictors of knowledge, attitude, intentional behaviour and concepts related to neurodiversity.

Effectiveness of a specifically conceived autism acceptance intervention (Chapter 12) – This study aimed to evaluate the effects of an intervention on peers’ self-report of knowledge of autism, attitude and intentional behaviours towards those with ASD and concepts of neurodiversity.

1.5 Conclusion

The secondary school experience for students with ASD represents a complex field of study, with multiple within student and environmental factors influencing the experience. The literature reports this to be a challenging time for students with poor post-secondary outcomes giving testament to this. However, there is a dearth or research reflecting these complex factors and how they may influence and relate to the student’s experience. There is much to be understood and it is complex in its dynamics.
This thesis attempts to gain insight into some of these factors, with a particular focus on understanding the social environment and peer group. It is envisaged that this will provide important and useful information.
Chapter Two: Autism Spectrum Disorder

2.1 Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disability. It is defined by diagnostic criteria and identified by deficits in social communication and interaction, and restricted, repetitive patterns of behaviour, interests or activities (APA, 2013). Children with a diagnosis of ASD are now estimated to represent at least one in 68 children (Christensen et al., 2016). This large representation within the school going population particularly challenges educational systems to respond to the needs of these individuals in an evidence based and informed manner.

2.2 History and Nomenclature of Autism Spectrum Disorder

In the 1940’s two eminent psychiatrists named and described autism, Leo Kanner in 1943, in the United States of America and Hans Asperger in 1944, in Austria. The term autism is derived from Greek and was intended to reflect the self-centred and isolating quality of their patients. Kanner (1943) originally described 11 children who demonstrated disturbances in communication and social interaction. Kanner additionally described the biological nature of autism, defining the condition as existing from birth. He went on to specifically highlight the importance of self-isolation and insistence on sameness as distinguishing features from other developmental disorders (Eisenberg & Kanner, 1956). Hans Asperger’s reports from Vienna account similar observations, most clearly the patient’s apparent detachment from other people, their love of ritual and routine, and some lack of awareness to the unspoken cues of others. Asperger gave descriptions solely of boys who had good verbal skills and no cognitive difficulties.
(Asperger, 1944). The traits described by both men are important elements of today’s Diagnostic and Statistical Manual of Mental Disorders (DSM-v) diagnostic criteria for Autism Spectrum Disorder (Table 2.1).

These early accounts primary purpose were to describe and characterize the condition. By the 1960’s and 1970’s there was a shift towards understanding prevalence and developing diagnostic tools. The first published prevalence study in 1966 estimated rates of 4.5 per 10,000 in eight to ten year old children (Lotter, 1966). In 1979, Wing and Gould (1979) conducted an epidemiological study of autism in the UK. They surveyed the caregivers of 132 children who exhibited one or more of the three core symptoms (i.e., impaired socialisation, abnormal language development and/or communication deficits, and restricted repetitive behaviours and interests) and/or met criteria for intellectual disability (ID). They analysed general rates of impairment, how these symptoms were related to presence or absence of ID, and how the symptoms could be categorised. Wing and Gould (1979) distinguished three categories of social impairment i.e., passive, aloof and active but odd. Wing later added “eccentricity and social awkwardness” to the categories. Wing and Gould (1979) suggested that the definition of autism be widened to incorporate larger numbers of impairments in social interaction. They proposed the triad of impairment that became an important demarcation of autism. The triad included, impairments in social interaction; impairments or complete absence of language and communication; and impairment in flexibility and imagination. These findings led to the creation of a new category of disorders that included autism and several other childhood disorders known as pervasive developmental disorders (PDD). In the 1980’s Wing also developed the term Autism Spectrum Disorders (ASD) which covered the range of developmental disorders with ‘autistic’ features in common (Jordan, 2005).
Two important early misconceptions about autism were also corrected in the 1970’s. Firstly researchers confirmed that many people with autism also have intellectual disabilities (Bartak & Rutter, 1976; Wing & Gould, 1979). It was also clarified that autism was not a form or a precursor to Schizophrenia (Rutter, 1972). Independently Michael Rutter and Edward Ritvo also clarified the main symptoms of autism and the three core features of triad of impairment (Ritvo, 1976; Rutter, 1978).

In 1980, autism was first recognised by the American Psychiatric Association as a disorder in the Diagnostic and Statistical Manual third edition (DSM-III). It came under the classification of Pervasive Developmental Disorders (PDD) as Infantile Autism (Volkmar & Reichow, 2013). Wing and Gould’s (1979) work heavily influenced a revision in 1987, to reflect the triad of impairment. The DSM-III-R (1987) also changed to Autistic Disorder from Infantile Autism. It is suggested DSM-III-R may have led to over diagnosis of autism in individuals with greater cognitive disability while under diagnosing at the other end of cognitive ability (Volkmar & Reichow, 2013). The late 1980’s also saw a growth is the understanding of theory of mind and its influence on the autism presentation, mainly through work of Uta Firth and continued into the 1990’s by Simon Baron Cohen.

In 1994, The DSM-IV aimed to balance sensitivity and specificity across cognitive and age ranges. The DSM-IV also focused on matching diagnostic criteria with the ICD-10 (WHO, 1992). The DSM- IV included three new disorders: Childhood Disintegrative disorder (CDD), Asperger’s disorder, and Rett’s disorder along with a sub threshold PDD- NOS (not otherwise satisfied) category.

With specific reference to Asperger’s disorder, Wing (2001) highlighted some of the main differences between Asperger’s Disorder and autism. This was that autism involved more severe impairments in socialization and communication than Asperger’s
Disorder. While children with autism were “aloof and indifferent,” children with Asperger’s Disorder were “passive or inappropriate” towards others. Children with autism often appeared uninterested in social interaction, but children with Asperger’s Disorder tried to socialize. With regard to communication, children with autism often failed to develop functional language, whereas those with Asperger’s Disorder struggled more with comprehension and content. The children with autism tended to display more repetitive behaviours and preoccupations, while those with Asperger’s had special interests or activities that preoccupied them (Wing, 1981). A consensus prevailed that the Autism diagnosis trumped Asperger’s disorder. Empirical research did not support the diagnostic validity of the DSM-IV criteria for Asperger’s Disorder (Tryon, Mayes, Rhodes, & Waldo, 2006). The distinction between autism and Asperger’s Disorder became a controversial point with the 2013 publication of the DSM-V (APA, 2013). The DSM-V groups Autistic Disorder, Asperger Disorder, Childhood Disintegrative Disorder and PDD-NOS into one diagnosis called Autism Spectrum Disorder (APA, 2013), see table 2.1. A second disorder, social (pragmatic) communication disorder, was added, although its direct relationship to autism spectrum disorders (ASD) is unclear (Volkmar & Reichow, 2013).

The 1990’s and 2000’s also saw an increase in treatments and scientific research into so called “cures” and causes of autism. Scientific research into genetic links and causative neurological factors remains a significant contributor to autism research outputs (Singh, Illes, Lazzeroni, & Hallmayer, 2009). Parental pressure and the formations of organisations such as Autism Speaks (www.autismspeaks.com) in the United States saw a shift towards funding and pressure to find a “cause, treatment and cure” for ASD. In the UK an analysis of 106 funding grants made between 2007 and
2011 demonstrated that projects in the areas of biology, brain and cognition far outweighed all other areas of autism research (Pellicano, Dinsmore, & Charman, 2014).

The last decade has seen a swing towards a greater emphasis on evidence based treatments and translational research which can impact the lives of those with ASD (Singh et al., 2009). The autism community and stakeholders expressed this through a piece of research carried out by Pellicano et al. (2014) which listed the following themes as their priorities for autism research; developing life skills, effective services, thinking and learning, place of autistic people in society, co-occurring conditions, treatments, life span issues and gender differences. The emergence of neurodiversity as a concept and movement has also shifted thinking and research outside of traditional health and educational models into a more biopsychosocial model (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). The biopsychosocial model is representative of the conceptualisation of disability by the World Health Organisation (WHO), international classification of functioning, disability and health (ICF) (2001).

An Australian sociologist and autism activist, Judy Singer, is credited with initiating the Neurodiversity Movement. She devised the term “neurodiverse” for those with neurological difference, looking toward making society more inclusive of autism as opposed to trying to ‘eliminate’ it (Baron-Cohen, 2017). Baron-Cohen (2017) argues that the concept of “neurodiversity” encourages society to recognise autism as an example of diversity in the set of all brains. He points out that neurodiversity provides a framework that does not focus on struggles or disorders but gives equal credence to what a person can do. It also views a person with ASD’s diversity or variation as intrinsic to their identity and sense of self, which is about human rights and respect. In his view, this movement may well be the major influencer on the next iteration of the DSM (Baron-Cohen, 2017).
2.3 Nature of Autism Spectrum Disorder (ASD)

2.3.1 DSM V (APA, 2013)

Autism is a complex, pervasive, and multifactorial neurodevelopmental condition (Masi, DeMayo, Glozier, & Guastella, 2017). Autism has been consolidated as a single Autism Spectrum Disorder (ASD) away from discrete subtypes or subcategories with the publication of the DSM V criteria. Levels of severity are classified according to levels of support the individual with ASD requires. There are three levels of severity: Level 1 requiring support, Level 2 requiring substantial support and Level 3 requiring very substantial support. The level of severity is based on social communication and interaction impairments and restricted, repetitive patterns of behaviour, interests or activities. The symptoms of autism must be present in the early developmental period although they may not manifest until adolescence or adulthood, see Table 2.1. Symptoms must also cause clinically significant impairment in social, occupational, or other important areas of functioning for a diagnosis of ASD to be made. The presence or not of an intellectual disability should also form part of the diagnosis (APA, 2013). There has been some concern that estimates of severity based on required levels of support could result in environment or site-specific application of the level. Environmental demands may exceed the capacity of the individual to function with or without support, for example a new school environment could demand higher levels of support, whilst the home environment remains stable. Also for individuals with mixed levels of impairment across specific core symptoms, functional skills and cognitive skills there may be great variation in levels of support they require, depending on task and environment (Weitlauf, Gotham, Vehorn, & Warren, 2014).
Table 2.1 *DSM V Diagnostic Criteria for Autism Spectrum Disorder*

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Social communication</th>
<th>Restricted repetitive behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Persistent deficits in social communication and social interaction across multiple contexts, currently or by history.</td>
<td>Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following:</td>
</tr>
<tr>
<td>Illustrative examples of symptoms</td>
<td>(1) Deficits in social-emotional reciprocity, ranging from abnormal social approach and failure of normal back-and-forth conversation, to reduced sharing of interests, emotions, or affect, to failure to initiate or respond to social interactions.</td>
<td>(1) Stereotyped or repetitive motor movements, use of objects, or speech.</td>
</tr>
<tr>
<td></td>
<td>(2) Deficits in nonverbal communicative behaviours used for social interaction, ranging from poorly integrated verbal and nonverbal communication, to abnormalities in eye contact and body language or deficits in understanding and use of gestures, to a total lack of facial expressions and nonverbal communication.</td>
<td>(2) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour.</td>
</tr>
<tr>
<td></td>
<td>(3) Deficits in developing, maintaining, and understanding relationships, ranging from difficulties adjusting behaviour to suit various social contexts, to difficulties in sharing imaginative play or in making friends, to absence of interest in peers.</td>
<td>(3) Highly restricted, fixated interests that are abnormal in intensity or focus.</td>
</tr>
<tr>
<td></td>
<td>(4) Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment.</td>
<td></td>
</tr>
</tbody>
</table>
Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

These disturbances are not better explained by intellectual disability or global developmental delay.

Specifiers

With or without accompanying intellectual impairment.

With or without accompanying language impairment.

Associated with a known medical or genetic condition or environmental factor.

Associated with another neurodevelopmental, mental, or behavioural disorder

With catatonia.

### 2.3.2 Gender

A persistent feature of ASD is that it is more commonly diagnosed in boys than girls. The DSM-V (APA, 2013) refers to a 4:1 gender ratio, males to females. Loomes, Hull, and Mandy (2017) carried out a meta-analysis based on previous prevalence studies to investigate this. Their findings confirm this ratio. Although it is pointed out that in studies were children were screened for ASD the ratio is likely to be slightly higher for girls. It is also considered that ASD may be under diagnosed in the female population (Dworzynski, Ronald, Bolton, & Happé, 2012).

### 2.3.3 Heterogeneity

Despite common areas of deficit or symptoms of autism that identify ASD as a condition, individuals with ASD show a vast clinical variability in these areas of deficit. The severity of symptoms and how they are conveyed vary hugely from individual to individual (Pelphrey, Shultz, Hudac, & Vander Wyk, 2011). For example, some individuals with ASD present with significant deficits in social interaction skills whilst
others may struggle with the very subtle nuances of complex social interaction. Although not surprising, it is an important factor in the development of interventions and assessment tools. This heterogeneity also drives and confounds much of the genetic research into aetiology (Devlin & Scherer, 2012). Heterogeneity is also represented in the broad range of intellectual or cognitive ability represented by those with ASD. Prevalence studies from the United States indicate 31% of children with an ASD diagnosis also had an intellectual disability (ID), with an additional 23% in the borderline ID range (Christensen et al., 2016). The heterogeneity or variability in presentations of autism symptoms is thought to be an expression of a complex interaction between genes, the brain and behaviour which is influenced by factors in the environment and most heavily by development (Pelphrey et al., 2011).

2.3.4 Co-occurring Conditions

The variability or heterogeneity in the presentation of ASD is further complicated by the common occurrence of co-occurring (sometimes referred to as co-morbid) conditions alongside ASD. Frequently identified psychopathologies alongside ASD include social anxiety disorder, oppositional defiant disorder and attention deficit hyperactivity disorder (Mannion, Leader, & Healy, 2013; Masi et al., 2017; Simonoff et al., 2008). Commonly co-occurring medical conditions include immune system abnormalities, gastrointestinal disorders, mitochondrial dysfunction, sleep disorders and epilepsy (Mannion et al., 2013).

2.4 Prevalence

Prevalence rates of ASD are an important area for research and enquiry. Prevalence rates have risen greatly over the last number of decades. Understanding reasons for this
and accurate estimates of incidence are considered vital for the development of services and interventions. Increase in prevalence rates also drives economic investment and prioritisation of those with ASD in policy reform. ASD is considered the fastest growing disability in the United States, and changes in diagnostic criteria are considered a major factor in this (Fombonne, 2009). The most recent estimate for the United States is that 2.4 percent of American children between the ages of three and 17 years or one in 41 children present with ASD (Xu, Strathearn, Liu, & Bao, 2018). The Centre for Disease Control (CDC) in United States reports a prevalence rate of one in 68 children having an ASD in 2014 (Christensen et al., 2016). This is an increase from previously reported rates of between 67 and 34 per 10,000 children in 2004 (McCarthy, 2014). In the UK, Baron-Cohen et al. (2009) reported a prevalence rate of between 94 and 99 per 10,000 school children. Australian studies have similarly reported increases in the frequency of ASD diagnoses over time, with the prevalence of ASD in children under seven years found to be 1.5 percent in a cohort born in 1999–2000 and 2.5 percent in a cohort born in 2004–2005 (parent reported) (Randall et al., 2016).

2.4.1 Prevalence of ASD in Ireland

Although there have been a limited number of studies examining prevalence or population screening studies in Ireland, a similar pattern to the US and Europe can be seen in figures published in 2016 (Boilson, Staines, Ramirez, Posada, & Sweeney, 2016). A screening study of Irish primary school students attending national / primary school aimed to operationalise and implement a European wide protocol for screening children for ASD using the Social Communication Questionnaire – Life time form (Rutter, Bailey, & Lord, 2003). Results from this study showed a prevalence rate of one in 100 for Irish primary school children.
2.4.2 Factors that Affect Prevalence Estimates

The increase in reported rates of autism, particularly over the past decade are accounted for by a number of factors. Fombonne (2009) discusses the broadening diagnostic criteria as an important factor. One of the challenges for analysing and understanding the data is the many and different ways prevalence is studied (Baird et al., 2006; Fombonne, 2009). There is an important point about increased awareness, which may mean that some children are receiving diagnostic assessment because of a better understanding of the presentation of autism in individuals. Contrary to this is that autism awareness remains quite poor in many sections of society and geographic locations and as such could be an argument for reported rates being even higher (Christensen et al., 2016). Systems of surveillance and screening of children have also become more developed and widespread which is a strong argument for identifying more children with ASD, although this can be regional and economically driven and with improvements in early childhood developmental screening more children may be diagnosed (Boilson et al., 2016). Estimating prevalence rates has proven to be a more challenging task than perhaps first envisioned, with changes to diagnostic criteria, nomenclature and evaluation methods being key influencing factors. Economic and social factors may also influence prevalence rates in the future. With large pockets of societies and countries where ASD is still less well understood and diagnosed, delays and waiting list for diagnosis as well as increased autism awareness, actual rates may be even higher than suggested by the CDC (Christensen et al., 2016).
2.5 Adolescence, Puberty and Autism Spectrum Disorder (ASD)

The period of adolescence is associated with much intellectual, emotional, psychological and physical change. The developments which occur during adolescence are a rich example of the combination of intrinsic and contextual influences on development. Puberty is a time of great biological change in the human body. Intrinsically the brain changes during adolescence and there is a rapid advancement of mental ability. Emotional and social developments are more context dependent and relate directly to the environmental influences on the young person. Regardless of the level of this emotional and social development, biological changes occur, sometimes causing an asynchrony between pubertal changes and social adjustment. The nature of social support and relationships becomes key to a well-adjusted adolescence. Parents, peers and teachers generally make up the key relationships of adolescence, with a shift to reliance on friends and peers and away from parents and teachers (Cobb, 1995).

While the physical developments associated with puberty are common for all adolescents, the psychosocial development of adolescents with ASD differs. Much of the current research reports on the development of adolescence with ASD have a strong emphasis on changes in their ‘impairment’ or pathology. Schall and McDonough (2010) describe the characteristics of autism in adolescence and early adulthood. It appears that individuals with ASD who have higher engagement with peers without disabilities show improvements in social communication particularly during adolescence. They also report that there is often a progression in language and communication during adolescence, perhaps reflecting the biological brain development of adolescence. There is evidence that some of the more stereotypical patterns of behaviour, activities and interests subside somewhat with adolescence development. However, there is also a reported increase in anxiety disorders, depressions and other psychopathologies (Schall
Although described in the context of the young persons’ with ASD diagnostic characteristics, it is noted that the reported areas of improvement are more likely to be associated with brain development and growth, whereas the areas of psychopathology may have a causality more closely linked to contextual factors, particularly in the social environment. Just as typical adolescence can experience adjustment difficulties between their biological development and social demands, sometimes causing the documented “storm and stress” of adolescent behaviour (Arnett, 1999), so too can young people with ASD. Many of the solutions to adolescent angst appear to lie in improving the “person–environment fit” (Eccles & Roeser, 2011). If the person - environment fit works for the typical adolescent, it may be a very different fit or accommodation which needs to be made for the adolescent with ASD (Davis, 2009). McGovern and Sigman (2005) report similarly that the diagnosis of ASD appears to remain static into adulthood, but behavioural, emotional and social skills change over time. There is also evidence from their longitudinal study that the children with ASD who had more peer engagement showed more developments in social skills going into adolescence. Peer engagement appears to be an important contextual factor in the development of social skills in both typically developing and ASD children. While improvements and change of core characteristics are evident in adolescence, they are seldom enough to change the diagnosis of ASD (Billstedt & Gillberg, 2005). Further thought must also be given to the fact that intervention throughout childhood may mean that adolescents with ASD develop compensatory functions and display typical behaviour through atypical pathways (Fein et al., 2013). Traits such as planning, working memory and organisation become more important during adolescence as the secondary school environment places increased demands in these skills (Rosenthal, et al., 2013). While impairments exist for adolescents with ASD, research has shown that
there may be few differences in the moods and feeling of typically developing adolescent and adolescents with ASD (Russell et al., 2012).

2.6 Conclusion

This chapter has introduced the presentation, prevalence and course of ASD into the adolescent years. It provides a background to understanding the aetiology and presentation of the participants with ASD in the studies presented in this thesis, with recognition that adolescence is a time of change for individuals with ASD impacting core difficulties and psychological adjustment. The following chapter will give perspective to the educational context for students with ASD in Ireland.
Chapter Three: Irish Education Context

3.1 Introduction
Since 2001 education practice in Ireland for students with ASD has taken an inclusive approach. Research evidence and an understanding of the pervasiveness of the challenges that autism brings continue to drive and develop policy and practice (Daly et al., 2016).

3.2 ASD and Educational Policy and Provision
A number of strategy and policy documents relating to educational provision and ASD have been developed and published in Ireland since the early 2000’s. Signing of the Salamanca statement at the UNESCO world conference on Special Needs Education in 1994 influenced inclusive educational policies. Of particular note is the report on the Task Force on Autism (DES, 2001) that recognised the constitutional right to education and made several recommendations in relation to education and supports. A report by the HSE in 2012 acknowledged that services for children with ASD lack cohesion and consistency particularly between the health and education systems (HSE, 2012).

Within the Irish context, the government has recognised those with ASD as a group of students with distinct needs. The Report of the Task Force on Autism, found that students with ASD were not having their needs met within the second-level educational options that were available to them at the time (DES, 2001). This was as a result of either gaps or an absence of appropriate provision and support for students with ASD or with schools not acknowledging the extent of the impairments that could be present with ASD. The report advocated that students with ASD receive specific provision in a setting that is appropriate to their needs. The Task Force recommended
that students with ASD should receive a continuum of educational options that best suits their needs, ranging from full time mainstream classes in a mainstream school to full time in a special school. The Task Force on Autism (2001), the EPSEN Act (2004), the Disability Act (2005) and the establishment of National Council for Special Education (NCSE) in 2005, have influenced the Department of Education’s policy of inclusion. Students with ASD are encouraged to attend local schools with support. It was estimated in 2014/15 that 8,739 students with ASD attend mainstream primary or post primary schools, this represents a significant increase from the 2008/09 estimate of 2,741 pupils with ASD attending mainstream education (Daly et al., 2016; Parsons, Guldberg, et al., 2009). In 2016 there were 3,137 mainstream primary schools, 141 special schools and 732 post-primary schools in Ireland (Daly et al., 2016). There are 19 dedicated special schools for students with ASD, 95 special pre-primary classes, 378 primary special classes and 152 special post-primary classes for students with ASD. There are also special classes for students with ASD in special schools. Some students with ASD are also reported to be home schooled (Daly et al., 2016)

The state provides Special Needs Assistants (SNA) to children with ASD in the school system and those in the mainstream system also receive 4.25 hours per week of allocated resource teaching hours.

3.2.1 The Education for Persons with Special Educational Needs (EPSEN) Act, 2004

The EPSEN act gives statutory effect to the rights of the child with special educational needs (SEN) to the same appropriate education as the child without SEN. The act states that a child with SEN should be educated in an inclusive environment with students
who do not have SEN unless the presence of the student in that class is detrimental to
the learning of the student themselves or the other students in the class (Ireland, 2004)

The EPSEN Act also provided a new statutory definition of SEN and confers
rights and entitlements on a greater number of students than under previous statutory
provisions due to a higher number of more comprehensive descriptors (Education,
2006). The act was envisioned to be implemented over a period of five years, however,
to date this has not fully occurred. Despite this, the full implementation is still regarded
as a priority for Irish educational policy.

3.2.1.1 Provision of Support

The support students with SEN receive from the State is important, as it should enable
the student to participate in school life at a level similar to that of their peers without
SEN. The level of support the student receives depends on their assessed level of need.
The NCSE, provides SEN support to schools through local Special Educational Needs
Organisers (SENOs) The main supports provided by the NCSE are resource teachers,
learning support, Special Needs Assistants (SNAs), adaptive equipment, assistive
technology and transport (DES, 2006)

3.3 Educational Placement

The educational context for students with ASD is typically the mainstream school, with
classes ranging from mainstream on a full-time basis to special classes on a full-time
basis. A 2016 research report from the NCSE, commissioned by the Minister for
Education and Skills in 2013, gives a comprehensive and largely positive overview of
educational provision for students with ASD in Ireland (Daly et al., 2016). Of particular
relevance were the findings in relation to Post-Primary/Secondary school provision to students with ASD. It was representative of five secondary school sites, including interviews with staff and students (with ASD). In general, the reported findings are of good practice and facilities. Gaps were identified in documentation and individualised planning at curricular level. The schools were praised for inclusive practice and ASD friendly special classrooms, there was concern in relation to whole school facilities and mainstream teachers’ knowledge and understanding of ASD (Daly et al., 2016).

Placement options for students with ASD in mainstream school are usually as follows.

### 3.3.1 Mainstream Class in a Mainstream School

Within this provision, the student is placed in the mainstream class with their non-SEN peers. They are taught by the class teacher, either with curriculum differentiation, co-teaching, or the presence of a resource teacher or learning support. The most typical presentation is the presence of a learning support or resource teacher and a SNA (Parsons, Guldberg, et al., 2009)

### 3.3.2 Special Class in a Mainstream School

These are disability specific small classes, sanctioned by the Department of Education and Skills and NCSE, with defined student and teacher ratios. For ASD specific special classes, often referred to as “units”, the student usually attends some mainstream classes, while the ASD specific class typically consists of six students, one teacher and two SNAs (Parsons, Guldberg, et al., 2009). In their review of the role and operation of special classes, Ware et al. (2009) report that resource hours assigned to schools are often used to establish ad hoc smaller, unsanctioned special classes for students who require them. Despite policy that students should be attending mainstream classes where possible, the review found that students were being placed full time in special classes in
the mainstream school (Ware, et al., 2009). While this may appear at odds with inclusive policies, parents reported that even though their children were not in a mainstream class, they were in a mainstream school, which was equally as important to them (Ware, et al., 2009). However, specialist ASD provision in Ireland, while established, has little independent research surrounding it in terms of the operation of these classes and the influence it has on student outcomes and further research into the area has been called for (Parsons, Guldberg, et al., 2009).

### 3.3.3 Access to support

In order to qualify for support, the student must have a diagnosis of a condition that affects their learning needs, made by a health professional, that meets the criteria laid out in Special Education Circular 02/05 (DES, 2006). For students with ASD, a diagnosis must be made by a psychiatrist or a psychologist using ICD-10 or DSM-V criteria and a further multidisciplinary assessment to ensure their needs can be met in school. It is reported that schools and parents value the link between diagnosis and the provision of additional resources as it provides certainty that the student will receive the necessary supports (Bond, Symes, Hebron, Humphrey, & Morewood, 2016). Similarly, Humphrey and Lewis (2008b) found that the diagnostic label was accepted pragmatically as a provider of support and resources for students.

### 3.4 Conclusion

This chapter has given a contextual and legislative background to the provision of education to students with ASD in Ireland. It is noted that policy and provision rarely differentiate between primary and secondary provision. There has been a recent recognition that secondary school students with ASD may require further provision of
support and understanding with the publication of the 2016 review (Daly et al., 2016). The following chapter presents a perspective on the secondary school experience for students with ASD through reviewing published literature and studies.
4 Chapter Four: Students with ASD and the School Experience

4.1 Introduction

The experience of students with ASD of secondary school is presented in the literature from a number of perspectives. This chapter presents the research and factors that may influence this experience for students with ASD. It aims to specifically examine the experience of the student with ASD in relation to social and behavioural aspects and how these impact on school participation. The focus is not on the academic aspects of school which are not within the scope of this thesis. This chapter addresses the need for social supports and inclusion and how these may affect the student with ASD at school.

It should be noted that the term secondary school is used throughout and refers to the post primary school years, or the phase of schooling beginning in early adolescence. In the UK and Ireland this is most commonly referred to as secondary school, in other countries it may be called middle school / junior high and high school. This level of education is documented by The International Standard Classification of Education (ISCED) as level 2 and 3 (Unesco, 1997).

4.2 The student perspective

Temple Grandin (2006), an autistic woman who advocates for a greater understanding of the needs of individuals with ASD, provides personal insights into her experience of secondary school education. Grandin emphasises an understanding of learning styles specific to ASD and development of strengths as key to positive educational outcomes.

Much of the literature on the inclusion of students with ASD in mainstream educational settings argues strongly for more inclusive practices (Batten, 2005;
Frederickson, Jones, & Lang, 2010; Frederickson, Simmonds, Evans, & Soulsby, 2007; Humphrey, 2008; Humphrey & Lewis, 2008b; Jones & Frederickson, 2010; Leach & Duffy, 2009; Majoko, 2016; Roberts, Keane, & Clark, 2008; Simpson, de Boer-Ott, & Smith-Myles, 2003). In addition, there has been a growing emphasis on educational practices that increase skills or teach deficit skills e.g., social behaviours to students with ASD to improve the likelihood of inclusion in mainstream settings (McDonald & Machalicek, 2013). To date there is a small body of mainly qualitative work addressing the perspective of secondary school students with ASD on their school experience. However, this body of work does provide a rich resource of first-hand information and insights. Qualitative studies, which specifically focus on the students’ voice, reveal many similarities across these students’ perspectives (Hill, 2014; Humphrey & Lewis, 2008a; Saggers, 2015; Saggers, Hwang, & Mercer, 2011, 2012). Themes extracted from these studies demonstrate challenges for students with ASD in relation to teaching and support, peers, friendship and negotiating the social world, the school environment, stress and anxiety, identity and being an active agent and bullying and teasing.

4.2.1 Teaching and Support

Participants within qualitative studies have reported their perceptions of teacher understanding to be crucial to their participation in school (Saggers, 2015; Saggers et al., 2012). Students often perceived teachers not to be adequately trained to understand how best to help them (Hill, 2014; Humphrey & Lewis, 2008a).

4.2.2 Peers, friendship and negotiating the social world

Data from qualitative studies have also shown that students with ASD report feeling different to their peers (Carrington & Graham, 2001; Humphrey & Lewis, 2008a).
Humphrey and Lewis (2008a) demonstrated that students with ASD may construct views of themselves and their challenges through negative social feedback they receive from others’, especially peers. Participants reported experiencing social isolation and difficulties negotiating the social aspect of school life. Many expressed the view that developing friendships and social acceptance was a priority for them; but they often struggled to do this and reported feeling lonely and isolated in the school setting. For those who had friendship groups it was viewed to be a significant enabler to successful inclusion in school and a sense of belonging (Hill, 2014; Humphrey & Lewis, 2008a; Saggers et al., 2012).

4.2.3 The School Environment

Qualitative studies have highlighted specific aspects of the secondary school environment as “stressors” (Carrington & Graham, 2001; Humphrey & Lewis, 2008a). Noise, other students, long corridors and unexpected events were all reported as sources of anxiety for students. The sense that the secondary school environment is more chaotic than primary school was highlighted. It was overwhelming for many and they appreciated a place of sanctuary or quiet to retreat to within the school setting (Hill, 2014; Humphrey & Lewis, 2008a; Saggers et al., 2012).

4.2.4 Stress and Anxiety

Themes from qualitative studies have highlighted some of the sources of stress and anxiety for students with ASD. These include the multitude of sensory information presented together in the school environment, the lack of order and predictability, social contexts including speaking out in class and making social connections with others (Hill, 2014; Humphrey & Lewis, 2008a; Saggers et al., 2012).
4.2.5 Identity and being an active agent

Qualitative data have revealed a theme relating to emerging identity formation and independence (Baines, 2012). For some participants, identity formation was intrinsically linked to others’ views of them, and they felt defined by their diagnosis, but wanted to be ‘normal’ (Humphrey & Lewis, 2008a). Students also articulated how they watched others in order to try and understand social behaviour that they could then copy in order to fit in (Hill, 2014).

4.2.6 Bullying and teasing

All the qualitative studies reported that the majority of participants experienced forms of bullying and teasing e.g., (Hill, 2014; Humphrey & Lewis, 2008a; Saggers, 2015). This was viewed as a significant inhibitor to learning and developing a sense of school belonging. There was variation in the severity and regularity that the bullying and teasing was experienced (Humphrey & Lewis, 2008a). A considerable concern was that for some students ‘minor’ forms of bullying or teasing went unreported or unrecognised. Some students felt it was pointless to report it, whilst others only felt concerned when the bullying was overtly aggressive or threatening (Hill, 2014; Saggers, 2015; Saggers et al., 2012).

These qualitative accounts of the experience of secondary school provide a useful backdrop to the behavioural and social factors that are widely reported to impact on students’ with ASD school participation. Although these studies represent a small cross section of secondary school aged adolescents with ASD, it provides insightful first-hand information. The emerging themes are supported by other empirical research findings.
and together these data create strong arguments for addressing these needs through current evidence-based practices and the further development of effective interventions.

4.3 Student Variables

Associated factors and core features of ASD which are investigated as influencing factors on participation in education include cognition and language, challenging behaviour and social skills. For many of these studies the focus has been on preschool or primary school aged students. With understanding that the secondary school experience is quite different than the primary school setting, and that trajectories of ASD and adolescence can change over times, there is a caveat that some of these findings may not be applicable to the secondary school student.

4.3.1 Cognition and language

Jordan (2005) and Grandin (2006) point out that students with ASD often have very different learning styles and cognitive profiles compared to other students, leaving them cognitively disadvantaged within the mainstream classroom.

Aljunied and Frederickson (2011) investigated the extent to which cognitive factors are indicative of the level of support required for those with ASD in education. In this small-scale study (n=52) based in Singapore, it was determined that measures of intelligence significantly discriminated the groups of children requiring additional support. A “theory of mind” index discriminated those requiring additional social and behavioural support. This is seen to be an important factor when addressing a student’s ability to cope within the mainstream school setting, i.e., those students with stronger theory of mind abilities may have less difficulty adjusting to the social and behavioural demands of school settings (Aljunied & Frederickson, 2011). Similarly, White, Seahill,
Klin, Koenig, and Volkmar (2007) found cognitive ability and weaker communication skills to be predictive of specialised placement or schooling for students with ASD. Concern about the emotional well-being and academic (under) achievements of students with ASD attending mainstream primary schools in Australia was addressed by Ashburner, Ziviani, and Rodger (2010). The age profile was between six and ten years and a case-control research design was utilised (n=28 students with ASD, n=51 typically developing peers). Similar to the findings reported by previous studies, the group of students with ASD exhibited higher levels of emotional and behavioural difficulties than their peers. The students with ASD also had high rates of academic underachievement, 54% compared to 8% of matched peers. In conclusion, a high proportion of these students with ASD were struggling behaviourally, emotionally and academically within the mainstream school setting. Concerns that these difficulties may be exacerbated in secondary school due to the increased challenges were expressed (Ashburner et al., 2010).

It is known that language skills are an important factor in both social and educational adjustment for students with ASD (Jordan, 2005). The author also points out that much teaching is based in verbal delivery methods (Jordan, 2005). There is some evidence that students with ASD have a preference for more practical skills-based subjects in secondary school, and language may be a key factor in this preference (Grandin, 2006). Despite the proportion of children with ASD who do not develop spoken language ranging from between 19 and 59 percent, there is limited research addressing language skills as a factor in school participation (Fombonne, 2009). Studies demonstrate that better expressive language is associated with more functional behaviour. Chiang (2008) demonstrated that one in two children without functional expressive language use challenging behaviour as a means of communication in their
school environment. This link between challenging behaviours and language is further expressed in studies of problem and challenging behaviours.

### 4.3.2 Challenging Behaviour

Jones and Frederickson (2010) investigated behavioural characteristics (reported by peers, parents and teachers) that predict social acceptance and rejection in the classroom for students with ASD and a matched group of peers without ASD (n=86, mean age = 11 years 2 months). Sociometric measures revealed that students with ASD were less well accepted by their peers and had higher social rejection than matched peers. In terms of their behavioural profiles, the students with ASD were reported to have lower levels of pro-social behaviour and higher levels of social and emotional difficulties than their peers. There was no difference between the groups on levels of conduct problems and disruptive behaviours. Parent and teacher ratings were significantly higher for students with ASD on scales for emotional problems, peers problems and hyperactivity, but lower for pro-social behaviours. This study depicts the re-occurring theme of behavioural differences in students with ASD and how they may or may not influence school and social participation. Understanding these behavioural differences and their cause and effect within school settings is an important aspect to this.

#### 4.3.2.1 Defining challenging and problem behaviour

The labelling or nomenclature of problem behaviour lacks some clarity within the literature. Challenging behaviour is the preferred term (Matson & Nebel-Schwalm, 2007) but labels such as maladaptive, aberrant, externalising and problem are also used. Problem behaviour appears as a wider term of reference as it can include less severe
behaviours and behaviours related to anxiety or internalising. Challenging behaviour is more likely distinguished by externalising or disruptive behaviours and most often includes self-injury, stereotypies and aggression. Problem or maladaptive behaviour also commonly includes hyperactivity, irritability, aggression, oppositional conduct, self-injury, anxiety and depression (Lecavalier, 2006; Shattuck et al., 2007). Hanratty et al. (2015) describe problem behaviours as behaviours that create problems for or challenge the individual and / or those who care for them. Maladaptive behaviours are behaviours that interfere with everyday activities, and include self-injurious behaviour, withdrawal, uncooperative behaviour, aggression, and destruction of property (Shattuck et al., 2007). More specifically Emerson (2001) defined challenging behaviour as “culturally abnormal behavior(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or behavior which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.” (p. 3). Holden and Gitleisen (2006) also distinguish between challenging behaviours which are more or less demanding, based on the amount of support required to manage a behaviour and the amount of interference which is may cause.

4.3.2.2 Challenging and problem behaviour and ASD

Much of the knowledge relating to challenging behaviours is derived from studies of individuals with intellectual disability. However, challenging and problem behaviours are reported to impact on the quality of life of many people including those with ASD (Matson & Nebel-Schwalm, 2007; McTiernan, Leader, Healy, & Mannion, 2011). Challenging behaviours associated with ASD include stereotypy and self-injury. The highest incidence of challenging behaviour is reported for those with both ID and ASD.
(Holden & Gitlesen, 2006). Murphy, Healy, and Leader (2009) found over 82% of participants in a study of risk factors for challenging behaviour for children with autism in Ireland displayed challenging behaviour.

The area of challenging behaviour and ASD is also further complicated by the heterogeneity of ASD and considering whether challenging or problem behaviours are classified as co-morbid psychopathology (Simonoff et al., 2008). It is widely acknowledged that for any child or adolescence the presence of problem or challenging behaviours has negative implications. In more serious cases this can include to the physical wellbeing of the individual and those around them (Emerson et al., 2001). Challenging and problem behaviours impede participation in activities, socialisation and learning (Lecavalier, 2006). Research indicates that problem behaviours may be one of the major factors in influencing individuals with ASD abilities to develop and sustain enjoyable peer relations (Szatmari et al., 2009).

Anderson, Maye, and Lord (2011) examined maladaptive behaviours in a cohort of children / adolescents with a diagnosis of ASD. Their findings also confirm the link between ID and behavioural difficulty continuing into adolescence. The authors also demonstrated that social withdrawal increased with age for a substantial number of children and adolescents in their study, and this pattern was not linked to ID. This mirrors the findings of Shattuck et al. (2007) which demonstrate that social reciprocity remains a challenge into adulthood even for those whose core symptoms lessen. Baeza-Velasco, Michelon, Rattaz, and Baghdadli (2014) found that adolescents with a good evolution of social and communication skills have lower levels of problem behaviour patterns than those with weaker social and communication skills. Anderson et al. (2011) demonstrate that the converse is not necessarily true, i.e., low social-communication skills does not equate to more severe problem behaviours. This may indicate that
external factors such as the environment, interventions and activities available have an influence over displays of severe problem or challenging behaviour for those without ID, but weaker social and communication skills.

Indicators are that internalising behaviours especially depression and anxiety may be more common in older children and adolescents with autism. It is speculated that this may be related to an increasing awareness of disability or diagnosis, and also higher social expectations from peers and adults (Anderson et al., 2011; Shattuck et al., 2007). Adolescence is most notably a time of increasing social pressures and physiological change. For those with ID and autism it is also thought that there may be an increase in aggression, obsessions, destructive and repetitive behaviour (Gillberg & Steffenburg, 1987). One of the challenges of the published research in this area is that it is often conducted on clinical samples i.e., they require intervention for a behavioural problem or similar. Adolescents with ASD who are “doing well” are less likely to participate in research and therefore less in known about them as they are not part of clinical samples. The divide between having an ID or not also presents as an important demarcation in the literature. The trend is to either address those who are considered to have high functioning autism (HFA) / Asperger’s and typical cognitive development or look at those with ID often alongside others who would be classified as having a severe disability. Few researchers have examined this in relation to the spectrum of autism, but examples include Woodman, Smith, Greenberg, and Mailick (2015) and (Shattuck et al., 2007).

### 4.3.2.3 Challenging behaviour and co-morbid diagnoses

Several research studies have addressed challenging behaviour as part of comorbid psychopathology (Baker & Blacher, 2015; Kaat, Gadow, & Lecavalier, 2013; Kaat &
Lecavalier, 2013; Simonoff et al., 2008; Stratis & Lecavalier, 2015). Over the last
decade there has been an acknowledged impetus to examine the emotional and
behavioural difficulties of children with autism in terms of co-morbidity or
psychopathology. In 2008, it was estimated that as many as 70% of children with autism
have at least one comorbid psychiatric condition Simonoff et al. (2008). Baker and
Blacher (2015) found that in a sample of 13 year-old school students with a diagnosis of
ASD, IQ was not a protective factor for Disruptive Behaviour Disorder (DBD) and in
fact those with ASD scored higher than those with typical cognitive development on
every questionnaire and interview indicator of DBD. The authors also found that
comorbidity with Attention Deficit Hyperactivity Disorder (ADHD) occurred in about
50% and Oppositional Defiant Disorder (ODD) in about 25% of 13 year-olds with an
autism diagnosis.

Through review it appears that the prevalence of ODD in those with ASD is
approximately 21%, reportedly a higher rate than in those with typical development
(Baker & Blacher, 2015). The rate of Conduct Disorders as a co-morbid diagnosis with
ASD is reported as 5% which is equivalent to those with typical development (Kaat &
Lecavalier, 2013). Consensus is that anxiety disorders are the most prevalent co-morbid
psychiatric diagnoses for those with ASD, followed by ADHD, ODD and mood
disorders (Gjevik, Eldevik, Fjæran-Granum, & Sponheim, 2011; Simonoff et al., 2008;
White, Oswald, Ollendick, & Scahill, 2009). White et al. (2009) suggest prevalence
rates of anxiety disorders vary from 11% up to 84% in children with ASD. Symptoms
relating to hyperactivity and anxiety were the most commonly found in a study of
specific behaviour problems in a large non- clinically referred group of young people
with Pervasive developmental disorder (PDD) (Lecavalier, 2006). Scores on the
Nisonger Child Behaviour Rating Form (NCBRF), insecure/anxious subscale were
shown to increase with age peaking in the 12 to 13 year-old age group. Over 50% of participants in this study were not recorded to have behavioural or emotional problems on the NCBRF (Lecavalier, 2006). White et al. (2009) also report this increase of symptoms of anxiety with adolescence. Hebron and Humphrey (2014b) note that parsing externalizing and internalizing symptoms may not truly reflect the complexity of mental health difficulties for adolescents with autism, as often aggressive behaviours may be as a result of stress and anxiety from the unpredictable nature of their social contexts.

4.3.2.4 Challenging or problem behaviour and quality of life

Research in the typical population of adolescence has demonstrated challenging behaviour, problem behaviours and internalising can lead to difficulties with academic and social life and often lead to adult psychiatric difficulties (Galéra, Melchior, Chastang, Bouvard, & Fombonne, 2009; McLeod, Uemura, & Rohrman, 2012). For adolescents with ASD it is more difficult to directly link behavioural problems to quality of school and social life, as these areas are frequently affected by the core symptoms of autism and / or intellectual disability (Anderson, Liang, & Lord, 2014) and the known poorer outcomes for adults with Autism (Hofvander et al., 2009).

4.3.2.5 Protective Factors and social skills

A key aspect for intervention planning and research is to identify protective factors to challenging and problem behaviour for children and adolescence with autism. School belongingness was identified as a key factor by Vaz et al. (2014) for all students with and without disabilities in relation to maintaining positive mental health. It has been
shown by a substantial body of work that good peer relations, friendships and acceptance are core factors in a positive transition to secondary school, academic and social success for all students. They are also shown to be protective factors to depression, anxiety and loneliness (Kingery, Erdley, & Marshall, 2011).

Social or positive social abilities are also hypothesised to protect against problem behaviours. Social anxiety in young people with ASD has been linked to weaker social skills alongside physiological and environmental factors (Bellini, 2006). Lecavalier (2006) also demonstrated a relationship between positive social ability and lesser problem behaviours.

Macintosh and Dissanayake (2006) examined children with Higher Functioning Autism (HFA) and Asperger syndrome between the ages of 4 years 4 months and 10 years 10 months compared to their typically developing peers. Teacher reports showed that typically developing children displayed significantly higher levels of co-operative behaviour, assertion and self-control compared to the group of children with HFA and Asperger syndrome. Within the group of children with HFA and Asperger syndrome, those with reduced social skills also had more severe problem behaviours. These children also were observed to have more problems with hyperactivity and internalising symptoms compared to their typically developing peers. It is likely that problem behaviours adversely affect children’s abilities to develop satisfactory peer relations (Macintosh & Dissanayake, 2006). This may suggest a causality dilemma between weaker social skills and problem behaviours. Social skills or social competencies as measured as a core aspect of the ASD presentation are differentiated to the presence of social withdrawal or a lack of social adaptation which are more closely linked to environmental factors, such as the school setting.
### 4.3.2.6 School Setting and problem / challenging behaviour

One of the most impacting factors in the ability to participate successful in day to day school life for those with ASD is the presence of challenging or problem behaviours (Ambler, Eidels, & Gregory, 2015). Expulsion and dropout rates for students with ASD in the UK have been reported to be higher than average, and a key factor in this is the presence of challenging behaviours (Barnard, 2002). Researchers theorise that the stressors of the mainstream school environment, such as unpredictability of routine and demands for social skills may be an influencing factor in students with ASD high levels of behavioural problems (Ashburner et al., 2010; Reed, Osborne, & Waddington, 2011).

In one of the few studies looking specifically at secondary school, it was found that students displayed high levels of social and emotional difficulties, with a view that factors within the school setting may contribute to these (Osborne & Reed, 2011). It is suggested that the perception is often that students, particularly those with both ASD and ID cannot effectively participate in school life due to their behavioural challenges and lack the necessary social skills (Lyons, Huber, Carter, Chen, & Asmus, 2016). There is some evidence for younger children that inclusion hours decrease according to the severity of autistic symptoms and aberrant behaviour (Yianni-Coudurier et al., 2008). One of the issues is that although interventions for challenging behaviour are well documented, the causes and frequencies are less well understood or documented particularly for school aged children (Murphy et al., 2009). An additional issue is that specialist intervention for these behaviours is rarely implemented within mainstream school settings (Machalicek, O’Reilly, Beretvas, Sigmafoos, & Lancioni, 2007; Matson & Nebel-Schwalm, 2007).

Lyons et al. (2016) examined 137 high school students with problem behaviours and severe deficiencies in social skills, as measured by parent and teacher reports using
the Social Skills Improvement System (SSIS) (Gresham & Elliott, 2017). Participants must have attended at least one general education class to be included in the study.

Overall it was found that these students had considerable social and behavioural needs. The sub-group of students with ASD displayed the greatest area of need. Specifically, for teacher and parent rating of social skills and parent ratings of problem behaviours. Discrepancies between teachers and parents on their ratings of problem behaviours were identified which may be evidence for environmental specific behaviours i.e., to school and home. To date, this is the only published study that addressed social skills and problem behaviour of students with ID and ASD.

Hebron and Humphrey (2014b) recognise that individuals with ASD are at an increased risk of co-morbid internalizing and externalizing psychological symptoms, both endogenous and exogenous factors. Important exogenous reasons particularly relate to the secondary school environment including bullying, lack of social support and student teacher relationships. (Hebron & Humphrey, 2014b)

### 4.3.3 Anxiety and social competence

Much of the secondary school specific research highlights social competence and social skill as being important factor in students’ with ASD outcomes e.g., (Fortuna, 2014; Humphrey & Symes, 2011; Locke, Ishijima, Kasari, & London, 2010; Osborne & Reed, 2011). The evidence that older children have less overt challenging behaviours (Seltzer et al., 2004) may create a change in focus towards developing social skills and connections associated with the adolescence years. There is also an identified shift from the externalising behaviours or challenging behaviours to more internalised problems such as anxiety, depression, low self-concept and anger (Hebron & Humphrey, 2014b).

It has been found for those with HFA that there is a positive correlation between
internalising, specifically anxiety and externalising or disruptive behaviours (Farrugia & Hudson, 2006). Anxiety is widely found to be higher in adolescents with ASD at school than other comparative groups (White et al., 2009). It appears a specific issue for those with ASD in their adolescent years, and often presents alongside pessimistic styles of thinking (Farrugia & Hudson, 2006; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Samson, Hardan, Lee, Phillips, & Gross, 2015; White et al., 2009). Anger and frustration also commonly co-occur with anxiety (Ambler et al., 2015). Causes are hypothesised to relate to major problems with peer relationships at school which often correlate with reports of anxiety in students with autism (Farrugia & Hudson, 2006). Hebron and Humphrey (2014b) found that anger was more prominent than disruptive behaviour in their study of secondary school students with Autism, they hypothesise that challenging behaviours may be more aligned to anxiety, frustration and anger in adolescents with autism than to co-morbid conduct disorders.

Outside of the distinction between ID or not, factors such as age, gender, social communication skills and functional cognitive abilities have also been considered as relating to social competence (Beadle-Brown, Murphy, & Wing, 2006). Weiss and Burnham Riosa (2015) addressed the relationship of social communication skills and functional cognitive abilities for those with ID and ASD to thriving and wellbeing. Thriving is inversely correlated to maladaptive behaviour in typically developing children (Arbeit et al. 2014). Their study demonstrated that for students with ASD and ID those who were thriving the least had weaker social communication skills and poor participation in home and school activities. The research points to the core deficit of social and communication skills putting those with ASD at greater risk of failing to thrive during their adolescent years (Weiss & Burnham Riosa, 2015).
In addition, it has been argued that the age at which a child develops language is the critical factor in their longer-term outcomes. Developing language skills before the age of five is found to predict better functioning into adulthood, including autism symptoms, adaptive behaviours and social skills (Pickles, Anderson, & Lord, 2014). Gender does not appear to play a huge role in outcomes and trajectories, with most studies not differentiating between boys and girls. Although, Billstedt, Gillberg, and Gillberg (2007) reported women with autism to have poorer outcomes in adulthood.

4.3.3.1 School factors, bullying and social support

The school environment is also thought to be influential over outcomes into adulthood. It has generally been found that an inclusive environment has a positive impact on adaptive behaviour, academic achievements and social peer interactions (Hunt & McDonnell, 2007). It is more difficult to ascertain if there is a direct relationship between changes in behaviours and core aspects of ASD and inclusive education practices. Woodman, Smith, Greenberg, and Mailick (2014) in their prospective, longitudinal study found that the experience of partial or full inclusion had a robust relationship with a positive developmental trajectory for individuals with ASD, including outcomes relating to maladaptive behaviours. An observation on much of the literature on the inclusion of students with ASD in mainstream school is that it relates to the quality of their social experience in school. Humphrey and Symes (2011) suggest this is due to the nature of ASD and the inherent difficulties students have with interaction and social skills. The results of these studies differ in their findings and focus, with some demonstrating positive results in terms of peer and teacher acceptance (Frederickson et al., 2007; Robertson, Chamberlain, & Kasari, 2003) and the majority reporting loneliness, isolation and bullying (Chamberlain, Kasari, & Rotheram-Fuller,
2007; Humphrey & Symes, 2010a; Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Locke et al., 2010). However, Symes and Humphrey (2011b) point out that much of this research is based outside of the UK (and Ireland), has restricted power and inference and often does not apply to mainstream secondary schools.

The experience of bullying has also been shown to relate to problem behaviours in schools (Hebron & Humphrey, 2014a). Behavioural challenges and issues are often the outcome of being the victim of bullying. Students with ASD are more vulnerable to being bullied (Begeer, Fink, van der Meijden, Goossens, & Olthof, 2016; Humphrey & Hebron, 2015; Zablotsky, Bradshaw, Anderson, & Law, 2012). Therefore, being the victim of bullying can cause both externalising and internalising behaviours and exacerbate problem behaviours for students with ASD.

Humphrey and Symes (2011) employed the Peer Interaction Observation Schedule (PIOS) to measure the amount of time students with ASD spent in peer interactions. Findings showed that students with ASD (n=38) spent more time in solitary behaviours, engaged in less co-operative interactions with peers and spent more time engaged in reactive aggression towards peers than comparison groups with dyslexia and no reported additional educational needs. There was an observed greater proportion of verbal aggression from peers towards those with ASD which explains the reactive aggression. A positive finding was observations of peers of students with ASD engaging in frequent instances of social initiations, however students with ASD did not always accept these initiations. Humphrey and Symes (2011) suggest that students with and without ASD would benefit from learning to recognise these social initiations and how to make social initiations in an explicit and tangible “ASD friendly” manner. The idea of educating peers is not new to the concept of inclusion, but rarely reported (Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001).
From the students with ASD perspective, Falkmer, Granlund, Nilholm, and Falkmer (2012) point out that knowledge of their perceptions of participation and the extent to which they desire to participate is limited. Falkmer and colleagues (2012) study of primary school age students demonstrated lower levels of participation, perceptions of being bullied, being less liked and less involved than their peers and less understood by their teachers. It was noted that comparisons with neurotypical peers or other disabilities may be too simplistic in these types of studies, if the students with ASD have different preferences for participation (Falkmer et al., 2012).

A large part of this drive to inclusivity is the view that social inclusion will be an outcome of inclusive education for those with ASD. The assumed social benefits may not be as easily found as anticipated. Certainly, literature reviews indicate that social benefits are not guaranteed and many students struggle to be accepted by peers (Lindsay, 2007). In the case of ASD, the inherent core social difficulties associated with the diagnosis further this struggle and the challenge of forming social connections within the school environment is extensively reported (Carter et al., 2014; Carter, Harvey, Taylor, & Gotham, 2013; Hedges et al., 2014; Kasari, Rotheram-Fuller, Locke, & Gulsrud, 2012; Rossetti, 2015). It is recognised that students with ASD have not benefited to the fullest in inclusive school environments, and a large factor in this may be others’ perceptions of them and negative attitudes from peers (Campbell, Ferguson, Herzinger, Jackson, & Marino, 2004). Frederickson (2010) discusses the perceived social benefits of inclusion to include reduction of stigma, the opportunity for social learning and copying of appropriate social behaviours from typical peers and engendering social acceptance, which may improve social standing within the school community. However, research to date has pointed to evidence that this may not be the case for students with ASD (Campbell & Barger, 2014).
4.4 Conclusion

Students with ASD face a number of challenges and opportunities within their secondary school life. Social, behavioural and emotional factors weave a complex pattern through attempts to participate and learn. Cause and effect for many of these factors is enmeshed in the complex social environment, the unavoidable changes that adolescence brings and the developmental and psychopathological path of ASD. The students themselves have alluded to many of these challenges through first person accounts. Whilst research and longitudinal studies dissect how intrinsic factors may impede or facilitate school participation, especially social engagement. With potentially more questions than answers emerging from understanding the individual student with ASD’s behavioural and emotional experience of secondary school, it is important to look at other key stakeholders’ perspectives.
5 Chapter Five: Parental Perspective

5.1 Introduction

Recent research has shown that parents of children with ASD will play a pivotal role in transition from primary to secondary school (Cremin, Healy, & Gordon, 2017; Dillon & Underwood, 2012; Peters & Brooks, 2016; Tobin et al., 2012). Parents of children with ASD report experiencing significant stress, particularly during times of transition and this can be impacted if challenging or problem behaviours are present (Koegel et al., 1992; Lecavalier, Leone, & Wiltz, 2006; Padden & James, 2017; Patton, Ware, McPherson, Emerson, & Lennox, 2018). This chapter will specifically examine how parents navigate the process of choosing a secondary school for their child with ASD, factors relating to parental involvement in the transition to secondary school and parental views on inclusive educational practice.

5.2 Parents and School Choice

Parental choice of secondary school is acknowledged as a key influencing factor in the educational experience for students with ASD (Bagley, Woods, & Woods, 2001). It has been widely discussed in relation to students with special educational needs (SEN) (Byrne, 2013). Often parental choice is heavily influenced by policy and provision in a particular country or jurisdiction (Byrne, 2013; Parsons, Lewis, Davison, Ellins, & Robertson, 2009). It has also been indicated that parent’s ideologies are an influencing factor; for example, Runswick-Cole (2008) suggest those who choose special education may be more closely aligned to a medical model, whilst those who chose mainstream are more aligned to a social model of disability. Lightfoot and Bond (2013) advice that this may be a simplification of a choice which is complex and influenced by many
factors. Murphy and Tierney (2006) also link school choice to social class and resources, with parents making pragmatic decisions to choose the school which offers the “best fit”. Byrne (2013) concludes that parents are mainly concerned with selecting a secondary school that best meet the needs of their child.

Parsons, Lewis, and Ellins (2009), looked specifically at parents of children with ASD compared to parents of children with other types of disabilities in the UK. There were few differences between the two groups. Overall most parents were satisfied with their child’s school placement. One significant difference between the parents of children with ASD and the comparison groups was in relation to transitioning between schools and choosing the right school. Parents of children with ASD were dissatisfied about availability and choice. Parsons, Lewis and Ellins (2009) suggest parents of children with ASD may require tailored assistance to ensure the needs of their children are understood by school staff and that the school environment can meet those needs. There appeared to be a strong wish by parents of children with ASD that their individuality is recognised, and that the child is understood and supported within the school context (Parsons, Lewis & Ellins 2009).

Other authors (e.g., Byrne, 2013; Lightfoot & Bond, 2013) describe parental frustration at a lack of information on deciding which educational setting is best for their child. Parsons et al. (2009) and Whitaker (2007) found that those who chose special school were more satisfied overall with their child’s experience. This is not surprising considering the difficulty mainstream schools often have meeting the individual needs of children with ASD. A re-occurring theme in the literature is the issue of mismatch between the schools’ offerings and the child’s needs. If school personnel believe that they lack the skills and training to meet the needs of many children with SEN, parent expectations that their children will be included and catered
for within the mainstream system is limited (Batten, 2005; Byrne, 2013). In the context of national and international policy and advice which promotes inclusion and mainstream education, it would appear that both sides concerns need to be addressed through research and service provision.

Although many parents report their desire to send their child to a ‘suitable’ mainstream secondary school, finding a school which meets their child’s needs is reported to be a difficult task. With much of the research reporting unmet information and education needs when it comes to selecting educational placement for their children (Whitaker, 2007). The process of finding a suitable secondary school and the factors which influence this are varied and complex for parents of children with ASD and other special educational need. Byrne (2013) presents the primary factors reported by nineteen research papers. Influencing factors relate to the child in terms of characteristics and levels of need, the parents specifically relating to socio-economic factors and the schools in terms of the child primary school experience, the capacity of the secondary school to cater to children with SEN and finally the influence of belief systems and opinions of family, friends and professionals (Byrne, 2013). It is important however to note that time and context may well have implications to the transferability of some aspects of the studies to the Irish context.

Other researchers have shown that these same factors or themes emerge, but with a greater emphasis from the parents about their concerns in selecting the appropriate school for their child (Cremin et al., 2017; Whitaker, 2007). Parents find their own schools, with reported lack of support or services. Parents also report high anxiety through this process and often a delay in finding the correct school (Jindal-Snape, Douglas, Topping, Kerr, & Smith, 2006; Parsons, Lewis, & Ellins, 2009; Tissot, 2011; Whitaker, 2007).
5.3 Transition

Looking specifically at the transition period from primary to secondary school, the literature clearly reflects this as a time of stress for parents of children with ASD (Dillon & Underwood, 2012; Hannah & Topping, 2012; Jindal-Snape & Miller, 2008). Tobin et al. (2012) point out that the transition period is critical to parental perceptions of the function of education for their child.

Dillon and Underwood (2012), focused on parents’ perspectives with a sample of 15 parents who participated in focus groups and in-depth interviews both pre- and post-transition in the UK. The small sample size and heterogeneity of autism impacts transferability of findings, as does the context in relation to Ireland. However, findings indicate that parents experienced this transition to secondary school with fear and in trepidation beyond that typically experienced. The major difference between this and a ‘typical’ child is that the sense of concern or anxiety alleviates as the child settles into school (Rice, Frederickson, & Seymour, 2011). For these parents concerns regarding their child’s experience of secondary school remained high. Recommendations put forward by the parents through the research included recognition of the heterogeneous nature of children with ASD and need for individual solutions tailored to each child, and a suggestion to schools to harness parent expertise. Tobin et al. (2012) identified similar themes from a parental perspective. The participant parents also reported that teachers typically did not understand their child’s diagnosis and needs or have the skills to manage their behaviours in the secondary school environment.

Generally parental concerns around the transition of their child with any type of SEN appear to revolve around two main aspects. First, that the new environment will lead to social isolation, a lack of understanding and potentially a widening of the social
gap between their child and other students. Second, a concern or beliefs about teachers in secondary school not having the skills, knowledge and capacity to educate or facilitate their child (Byrne, 2013).

5.4 Inclusion

Inclusion is recognised as a complex interaction between the child, family and school environment (Byrne, 2013). The overarching message from much of the research appears to be that the milder the child’s difficulties the more positive the parental views on inclusion are (Byrne, 2013). Therefore, a parent of a child requiring very specialist provision is more likely to assume a mainstream school will not be able to manage their child’s needs. Parsons, Lewis, and Ellins (2009) also reiterated this point with the majority of children in specialist provision having intellectual disability and complex needs. Parents of children with milder difficulties would more likely select mainstream placement options but caveated this by making the choice based on a perception of the school being able to meet their child’s needs, and not assuming that all schools can or will meet their need (Bagley et al., 2001; Byrne, 2013; Parsons, Lewis, & Ellins, 2009).

The dichotomy emerges as parents seek inclusive mainstream schools that can cater to the individual child’s needs, where the child would be happy and can manage problem behaviours and differences. Whilst many of the schools appear to have concerns over training and expertise to support students with ASD, with studies reporting that mainstream teachers believe that lack expertise to teach students with ASD, (Batten, 2006, Parsons, Lewis & Ellins, 2009; Whitaker, 2007).

A child’s experience of inclusion in primary school also seems to be an influencing factor. If a child was perceived to have had a poor experience of inclusion in a primary school, it may drive the parent to find a secondary school which may
provide a more inclusive experience or conversely transfer them to a special school. (Bagley, Woods & Woods, 2001; Runswick-Cole, 2008).

Overall there is a sense that inclusion in the secondary school environment is a more difficult concept to define and may differ in form and ideology to the primary school environment (Byrne, 2013; Tobin et al., 2012). The widening social and educational gap of the teenage years concerns parents and impacts on their perceptions of inclusion in secondary school.

Parental ideology is also recognised as a key influencing factors in parental choices of school and inclusive secondary education. Many parents of children with ASD and SEN raise the happiness of the child as a primary concern in secondary school (Parsons, Lewis, & Ellins, 2009; Whitaker, 2007). The differing values and goals parents place on the educational experience for their child, specifically for secondary school impacts on their perceptions of inclusion and ultimately school choice (Lightfoot & Bond, 2013; Runswick-Cole, 2008). Tobin et al. (2012) point out that choosing and moving to a secondary school often causes the parent to evaluate their views on inclusion for their child and the function which education plays in their child’s life. Weighing up social inclusion against academic achievement can often be the choice which parents of students with ASD have to make. The child’s primary needs often require definition within the construct of mainstream secondary education.

5.5 Conclusion

Parental role in school choice and their views on inclusion can directly influence the experience of school for a student with ASD. The transition period can be a particularly stressful time for both parents and students, particularly in relation to the new environment and how the student with ASD will be understood. Teachers and school
personnel have an important role to play in terms of their attitude towards and understanding of ASD and preparing the new educational context. Chapter 6 will discuss these issues further.
Chapter Six: Teachers, School Personnel and the School Environment

6.1 Introduction

Student’s school experiences are very dependent on their relations with teachers and school policies (Falkmer, Anderson, Joosten, & Falkmer, 2015). Poor relationships or struggles with inclusion can have detrimental effects on the student with ASD (Woodman et al., 2015). Factors relating to teachers and the school environment are an important dimension to understanding the secondary school experience for students with ASD. It is widely acknowledged that starting secondary school involves an adjustment to a far more complex social and academic environment, with less predictability and a lot more teachers than primary school, this is often a struggle for students with ASD (Hedges et al., 2014). It is the model of subject based structures and teachers assigned to subjects which can prove the most challenging in terms of inclusivity and understanding of ASD in secondary school systems (De Vroey, Struyf, & Petry, 2015). The students report great difficulty dealing with different teacher’s expectations of them and the inconsistencies of this (Hedges et al., 2014). Teachers have less opportunity to interact or collaborate with students. The focus on academic achievement also means that the critical social needs of many students with ASD are overlooked (Hedges et al., 2014). Teachers in qualitative studies have alluded to this, explaining that academic need will trump social need (Kucharczyk et al., 2015). Teachers observe that students with ASD are less likely to verbally respond to questions, make presentations or work collaboratively in groups with peers (Newman, 2007). A UK based study indicates similar findings through observations of pupils with ASD (Symes & Humphrey, 2011b). Teachers report that they do not feel they have the
expertise to intervene at this level or encourage group work and cooperation or intervene in socially awkward situations (Hedges et al., 2014; Newman, 2007).

### 6.2 Attitudes of Teacher

Attitude of the educator is reported by Segall and Campbell (2014) to be one of the most important factors for inclusion of students with ASD in the mainstream classroom. A small number of studies have looked at teachers’ and school personnel’s attitude towards the education and inclusion of students with ASD in schools. In general, the international published studies indicate more positive than negative attitudes towards including students with ASD (Gregor & Campbell, 2001; Humphrey & Symes, 2013; Robertson et al., 2003; Segall & Campbell, 2014). A Scottish-based study in 2001 surveyed 49 mainstream teachers and 23 special education teachers, revealing teacher concerns about the negative impact on other students and disruptions that students with ASD may cause (Gregor & Campbell, 2001). More recently Humphrey and Symes (2013) looked specifically at secondary school teachers and administrators (n=32 teacher and n= 21 managers and special needs coordinators). As the study also reported on experience and knowledge, the data specific to attitude are somewhat unwieldy, but it is reported that participants indicated overall mixed-moderate attitudes towards inclusion which were directly reflective of their experience of inclusion within the school they worked in (Humphrey & Symes, 2013). A qualitative study within an Irish context (McGillicuddy & O'Donnell, 2014) highlights how sometimes teachers with seemingly positive attitude to students with ASD in the mainstream secondary school environment, may actually serve as a barrier to the development of more appropriate and inclusive approaches to facilitating students with ASD. A theme of their research was that teachers reported a consensus that life in the mainstream allowed students to
prepare for the realities of life outside school. In effect, developing resilience and coping methods to adversity within school was considered to benefit students. McGillicuddy and O'Donnell (2014) point out that this belief or attitude may well prevent the improvement of school offerings to those with ASD. Overall the reported trend is towards more positive attitudes to the inclusion of students with ASD in mainstream secondary school, caveated by findings that those teachers who have specialised in supporting students with SEN and ASD may have attitudes more in line with inclusion, whereas subject teachers’ attitudes may be more in-line with a medical model, viewing those with ASD as a distinctive group requiring expert support (De Vroey et al., 2015).

6.3 Knowledge

It is recognised that teachers of students with ASD should have knowledge of ASD, including best practice in terms of strategies and facilitators for inclusive educational practice, but often education professionals lack accurate information about ASD (Segall & Campbell, 2012). Studies have indicated poor basic knowledge amongst teachers, but also the teachers themselves reporting that they do not have the skills or training to support students with ASD (Robertson et al., 2003; Segall & Campbell, 2012). Those with more specialism in working with students with special educational needs show higher levels of knowledge (Segall & Campbell, 2012). Hedges et al. (2014) conducted a qualitative study examining the following research question: “What is challenging about high school for students with ASD?” Teachers reported a general lack of knowledge about ASD and viewed this as a major barrier to students fulfilling their potential in secondary school. Certainly, parents identify teacher training and knowledge as a key factor in facilitating their child’s transition and participation in
secondary school (Dann, 2011; Jindal-Snape et al., 2006). Students with ASD also identify teacher knowledge as an important factor in their experience of secondary school (Humphrey & Lewis, 2008a; Saggers, 2015). Stakeholders including parents and teachers in a study by Kucharczyk et al. (2015) made strong recommendations for professional development, particularly for general education (single subject) teachers in order to understand ASD and interventions specific to ASD. Segall and Campbell (2012) reveal that mainstream teachers’ levels of knowledge is a strong predictor of awareness of best practices in inclusion and teaching of students with ASD. Perhaps more obviously, experience in the area of ASD is predictive of the use of empirically supported intervention models in the classroom. There is a potential danger in assuming that improved knowledge will change behaviour and attitude. Segall and Campbell (2012) and Humphrey and Symes (2013) draw similar conclusions in relation to this issue and recommend more training for teachers, specifically in inclusive practices, with an emphasis on targeting specific areas of need as opposed to generic information provision.

### 6.4 Experience

The relationship between experience, knowledge and attitude is demonstrated by extant research (Segall & Campbell, 2014). Teacher participants in McGillicuddy and O'Donnell (2014) were strong on indicating that experience, more than training, equipped them for working with students with ASD. However, they also unanimously agreed that mainstream secondary school teachers require more training and understanding of ASD. The challenge for mainstream teachers and more specifically secondary school teachers is gaining this experience and familiarity with ASD, so that they can be confident or equipped to work with students with ASD (Leach & Duffy,
A lack of confidence and self-efficacy contribute to teacher stress and anxiety, and a sense that the teacher cannot meet the needs of the child within the mainstream classroom (Gregor & Campbell, 2001; Robertson et al., 2003). It has been demonstrated that experience with ASD directly relates to attitudes towards inclusion (Gregor & Campbell, 2001).

Teachers with special education training or in specialist roles have the most experience and therefore greater self-efficacy and knowledge in teaching students with ASD (Humphrey, Lendrum, Barlow, Wigelsworth, & Squires, 2013). The challenge for secondary schools is to bring this experience and knowledge into the mainstream classroom so that participation or inclusion for students with ASD is an available option. Frederickson et al. (2010) demonstrate that schools in the UK with specific ASD support programs demonstrate higher use of whole school and individual strategies for the student with ASD; however, this study was carried out in a primary school setting. Osborne and Reed (2011) demonstrate findings that showed students’ sense of belonging and their socialisation in school was directly linked to teachers with greater self-efficacy in their competency with students with ASD. McGillicuddy and O'Donnell (2014) point to only the most experienced teachers in their qualitative study having knowledge of specialised intervention such as ABA or teaching social skills.

6.5 Post-Secondary Outcomes

A major impetus for attempting to understand the secondary school experience for students with ASD is revealed by the poor post-secondary outcomes for students with ASD (Levy & Perry, 2011). Reports are of students finding it difficult to attain work, access third level education and struggle to live independently. Such reports reflect badly on educational and personal gains in secondary school. International statistics
demonstrate these figures to be alarmingly high. In the US the enrolment rate of youth with autism was about 50% for any postsecondary education and 20% for a 4-year college (Newman, Wagner, Cameto, Knokey, & Shaver, 2010). Rates of employment are also significantly lower for those with ASD, and it is estimated that between 12% and 24% of youth with ASD are not engaged in any productive activities post-school (Shattuck et al., 2012). Recent data from the UK, reports slightly better outcomes, but was inclusive of those in mainstream education only. Findings from secondary data analysis report students with autism were more likely to leave mainstream education with lower educational achievements than their peers without autism. They were also more likely than their peers without autism to enrol in Colleges of Further Education rather than in Higher Education Institutes which offer higher levels of education outcomes (Dillenburger et al., 2016). These lower attainments point to secondary school systems which may not be facilitating students with ASD to meet their potential or obtain the practical life skills they may require in adulthood and the workplace. It is suggested that many students with ASD leave secondary school without the necessary skills, supports or experiences to prepare them for life after school and productive contributions to society (Shattuck et al., 2012).

### 6.6 School Context

Factors within the school itself include the ethos of the school, the nature of teaching and the school environment in terms of physical, sensory and social characteristics (Ashburner et al., 2010; Humphrey & Lewis, 2008b). The secondary school environment and transition to it is viewed as a challenging adjustment for students with ASD. An increase in pace of learning, moving from class to class and the overwhelming sensory environment are eluded to as challenges to those with ASD (McGillicuddy &
O'Donnell, 2014). Students are managed within this system as opposed to addressing changes which may support greater inclusivity (McGillicuddy & O'Donnell, 2014). Students with ASD report feeling overwhelmed and at odds with the chaotic and busy environment (Saggers, 2015). While teachers report observing that unusual or unfamiliar behaviours of the students with ASD can “annoy” other students and are poorly understood (Hedges et al., 2014; McGillicuddy & O'Donnell, 2014).

Osborne and Reed (2011) addressed the impact of some of the basic school factors on students in mainstream secondary school with ASD. The study included 105 participants with confirmed diagnosis of ASD attending 91 mainstream secondary schools in the UK. School variables collected related to the characteristics of the school, namely, school size, number of teachers, and number of pupils with special educational needs. Student variables were related to emotional and behavioural functioning. Overall the study reports high levels of behavioural and emotional difficulties in the sample of students with ASD attending secondary school. The results specifically related to the school factors reveal a mixed pattern. The authors summarise it as demonstrating that exposure to typically developing students improved social behaviours for students with ASD, exposure to students with SEN improved functioning in all areas except pro-social behaviours and exposure to learning support assistants negatively impacted social behaviours but assisted with behavioural and emotional problems. The question as to why the presence of other students with SEN is positive in terms of its impact for students with ASD is an interesting one. Osborne and Reed (2011) query whether greater numbers of students with SEN change school practice.

The finding in relation to teaching assistants (TAs) or special needs assistants (SNAs) is also addressed by Symes and Humphrey (2011a); their mixed methods study revealed similar findings in relation to TAs and secondary school participation.
Observations revealed that students with TAs were less likely to work independently and had fewer opportunities for socialising. It is suggested that although assistants are employed with the purpose of enabling inclusion, often their presence can have the opposite effect. This is partly related to a lack of training in facilitating inclusion, and the changing social and academic needs of the secondary school student (Symes & Humphrey, 2011a).

With regard to exposure to typically developing students and improved social behaviours for students with ASD, this area will be addressed in greater detail in the subsequent chapter. However, it is recognised that even where student teacher relationships do not impact on academic inclusion, they can still determine the degree to which students with ASD are socially included (Robertson et al., 2003). Teachers can therefore improve inclusive social relations by modelling positive accepting attitudes and demonstrating behaviours which embody a positive social ethos and friendships (Robertson et al., 2003). However, many teachers believe that they do not have a perceived role in this area; a view expressed by Irish teachers in qualitative research was that their primary role is around academic achievement for pupils, leaving a gaping void for social, emotion and behavioural interventions (McGillicuddy & O'Donnell, 2014).

Teachers who participated in McGillicuddy and O'Donnell (2014) articulated that a major concern for those with ASD was social inclusion. The teachers saw a social gap between those with and without ASD which increased with adolescence and progression through secondary school. They believed that improved awareness of ASD in the student body would be a positive step to further inclusivity and recommend educational programmes based on acceptance, acknowledgement and accommodation of students with ASD for the student body.
6.7 Conclusion

The research addressing teachers’ attitudes and knowledge reveals mixed findings. Knowledge and specific skills in working with students with ASD in secondary schools appears to be a particular challenge with a view that students should fit in to pre-existing systems. However, poor post-secondary outcomes indicate that students with ASD are disadvantaged by this model and are not fulfilling their social and academic potential (Odom, Duda, Kucharczyk, Cox, & Stabel, 2014). As a large and important part of the secondary school context are the students themselves, the next chapter will address the role of peers without ASD and their part in the experience of secondary school for students with ASD.
Chapter Seven: Peers and the Social Experience of Secondary School

7.1 Introduction

Inclusive education has evolved from a basic human right to an education alongside other students. A large part of this drive is the view that social integration with peers will be an outcome for those with SEN or disability. In the case of ASD the assumed social benefits may not be as easily found as anticipated. The inherent core social and communication difficulties associated with ASD seem to be the struggle to make social connections in the school environment, one which is extensively reported in publications and research (Carter et al., 2014; Carter et al., 2013; Hedges et al., 2014; Kasari et al., 2012; Rossetti, 2015). It is recognised that students with ASD have not benefited to the fullest in inclusive school environments, and a large factor in this may be others’ perceptions of them and negative attitudes from peers (Campbell et al., 2004).

Humphrey and Symes (2011) propose these frequent negative social experiences at school are the result of an interaction between the student with ASD, their impaired social and communication functions and their peers who lack understanding of the ramifications of ASD and how these students’ social skills may be affected. To this end any attempt to improve social experiences for students with ASD must consider both these elements. Raising peer awareness of ASD is seen as necessary to acceptance of those with ASD as part of the peer group or within social interactions.
7.2 The Social Experience

Campbell and Barger (2014) summarise the social experience of school for those with ASD as: 1) decreased social interaction, with more reported solitary time than typical peers; 2) Increased experiences of bullying and teasing; 3) Feeling more lonely and isolated in school than typical peers and 4) Having a perception of less social support and friendships than others.

Why students with ASD are having these negative experiences is a more complex question, but certainly outside of the inherent social and communication difficulties that these students most likely have, the reasons lie in the social behaviour and attitudes of their peers. Peers are reported to embody the most effective resource for shared social supports and participation in schools (De Vroey et al., 2015; Ochs et al., 2001).

Within the secondary school population reported personal or peer factors which can influence negative attitudes towards those with disabilities include adolescence itself, anxiety, fear of isolation, ethnocentrism and body concept (McDougall, DeWit, King, Miller, & Killip, 2004).

7.3 Attribution theory

Research suggests that peers who are unpopular or not accepted within the school social context frequently display aggression, anti-social behaviours, are often physically different and shy, in other words they display differences or idiosyncrasies. Students with ASD often fit into these categories. Students who are in some way different or idiosyncratic, but whose differences are understood or known to be outside of their control often elicit more sympathetic and accepting responses (Juvonen & Weiner, 1993).
Attribution theory explains the inconsistency in how students with special educational needs can experience discrimination and rejection by peers, whilst others receive positive and caring attention from peers. It partly appears to be related to peer perceptions of control. If the view or understanding is that a behaviour or act is outside the control or responsibility of an individual, it is more likely to conjure feelings of rejection, anger or ill will towards the individual. Whereas if the perception is that a behaviour or act is ‘not the fault’ of the individual, feelings of sympathy and positive social reactions are formed (Frederickson, 2010). Using attribution theory, it has been found that even for very young children, giving reasons and explanation for disability and difference produces more favourable attitudes and behaviour. Without explanation children do not react well to peers with hidden disabilities, e.g., Autism Spectrum Disorder, and they do not attribute their differences to a condition or something outside of the individual’s control. This is the formation of an argument for labelling and imparting knowledge about the ‘label’ or difference to peers in order for them to form more positive relationships with those they perceive as different (Frederickson, 2010).

Attribution theory also gives credence to the argument that improving student’s social skills does not necessarily improve their social standing. An intervention relating to understanding and perceiving the reasons for the student’s difficulties with social skills for peers is also required i.e., a contextual approach (Juvonen & Weiner, 1993).

This concept was captured by Campbell and colleagues (2004) who addressed knowledge, attitudes and intentional behaviours of peers towards those with autism. The authors demonstrated that detailed explanatory information about autism from a respected source, e.g., teacher or professional, had the most impact in terms of willingness to interact with a peer with autism (Campbell, 2006; Campbell et al., 2004). Notably, Campbell’s studies did not include students with autism and all of the
information provided was based on hypothetical cases of children. Frederickson (2010) argues that the use of co-operative learning and supports such as joint activities and buddy systems are also effective methods of encouraging positive peer interactions.

Sasson et al. (2017) also reflect on the snap judgements which can often be made by peers about those with autism. Such judgements based on very brief interactions may result in many students with autism being viewed as “odd”. The impairment in social interaction is therefore a relational one, as those without autism find it difficult to communicate socially with those with autism based on judgments and less favourable first impressions (Sasson et al., 2017). The reluctance of peers to engage in social interactions with their peers with ASD further limits the opportunities for students with ASD to practice their social skills.

### 7.4 Peer-mediated Strategies

The use of peers as a resource to facilitate interventions for their classmates with ASD is widely reported. The National Professional Development Centre on Autism Spectrum Disorder ([http://autismpdc.fpg.unc.edu/](http://autismpdc.fpg.unc.edu/)) lists peer-mediated instruction and intervention as an evidence-based practice.

Peer-mediated intervention are described as training peers (without ASD) of target children (with ASD) to deliver intervention protocols and act as agents of behaviour change (Young, Radley, Jenson, West, & Clare, 2016). There is a strong evidence base and the interventions appear promising for changing social behaviours of students with autism in school (Chang & Locke, 2016). Peer-mediated interventions show evidence for improving social skills (Watkins et al., 2015). However, these interventions are purely designed to focus on the students with ASD. Outcomes are based on measurements of social skill and behaviour change in students with ASD. In
terms of making social connections or any improvements in social standing or experiences for students with ASD, this has not been focused on. Peer tutors obviously learn a lot more about ASD and communications with students with ASD, but whether this acts as a stimulus to change social inclusion is unknown. These interventions also make use of a small number of peers who are selected for their own good social skills and high social status. They generally target students with ‘high-functioning’ ASD and there have been very few carried out in secondary schools, which could be argued to be the environment with most need (Chang & Locke, 2016). Therefore, although beneficial in terms of improving social skills, the other side of the social relationship i.e., the peer, remains unaccounted for. These interventions are not designed to improve ASD knowledge or acceptance and as such highlight further the importance of educating the peer group in terms of their social behaviours towards their peers with ASD.

Proximity may enhance social relations, but proximity or placement alone will not impact peer attitudes towards those with disability. Specific interventions are required to encourage interactions (De Vroey et al., 2015). There are also reports of peer buddy systems and classroom-based interventions, which are closer to addressing the dynamic nature of social relationships between those with and without ASD. A large body of work by Erik Carter and colleagues has looked into these types of peer network interventions in secondary school (Carter, Asmus, et al., 2016; Carter et al., 2014; Carter, Sisco, Brown, Brickham, & Al-Khabbaz, 2008). A study using peers as supportrs of learning to their peers with severe disabilities (including ASD) shows promising results. Certainly the benfits for classroom-based interactions and learning were very positve when compared to a comparison group. Students with peer support demonstrated gains in academic engagement, improvements in social goals and gains in social participations and friendships. Follow-up data demonstrated these friendships
endured beyond the period of the intervention. Both groups of students and their teachers reported positive experiences and personal gains. What is less clear are the outcomes outside of the classroom setting (Carter et al., 2016). Intervention and education approaches that target both those with ASD as well as their peers may offer a more comprehensive approach for improving social outcomes.

7.5 Autism Acceptance

Peer-mediated interventions are not designed to address a larger student body and it is known that a great number of students who do not understand behaviours and presentation of peers with ASD remain in the school environment (Campbell & Barger, 2014). Students with ASD report a desire for socially welcoming environments and the opportunity to express themselves and their identity (Humphrey & Lewis, 2008a; Saggers, 2015). If students with ASD are educated in inclusive settings and social connections are a challenge for them, it makes sense that other students are taught to know and understand ASD and the social challenges that a diagnosis of ASD may present. Students who are typically developing do not necessarily have the skills and confidence to make new social connections, especially with those who they view as different, and may need to learn more about their own communication style, knowledge and attitude in order to make those with ASD more accepted. Autism acceptance is defined by Cage, Di Monaco, & Newell (2017) as “an individual feeling accepted or appreciated as an autistic person, with autism positively recognised by other as self as an integral part of that individual” (p.474). There is some evidence for autism acceptance as a protective factor in the mental health of those with ASD; findings of an exploratory study point towards intrinsic and extrinsic autism acceptance as protective
against depression and sadness in adults with autism (Cage et al., 2017). It is a further argument for addressing knowledge and understanding autism with school-aged peers.

### 7.6 Peer Knowledge and Awareness of Autism

Peers’ lack of knowledge about ASD has been identified as an obstacle to social inclusion experiences for students with ASD (Campbell & Barger, 2014). Since 2000 there has been a small amount of focus on peer awareness or knowledge of autism, with a trend towards improved knowledge in more recent studies (Campbell, 2008; Campbell & Barger, 2011, 2014; Campbell et al., 2004; Campbell, Ferguson, Herzinger, Jackson, & Marino, 2005; Campbell, Morton, Roulston, & Barger, 2011; Silton & Fogel, 2012). Following on from the assumptions of attribution theory and a newer understanding of autism acceptance, it is important that peers have knowledge and awareness of ASD, and those who have ASD. Social rejection and anger is less likely directed towards those who are understood not to be behaving in a stereotypical manner ‘on purpose’.

Peer education about ASD is a less reported intervention. Explanatory school sessions about ASD are described particularly in Campbell’s (2004 & 2008) body of work. It is thought that explaining autism can provide peers with accurate information about the condition and correct misunderstanding or defective knowledge about those with autism and their behaviour. It is known that peers often attribute intentionality to behaviours such as social avoidance or stereotypies (Campbell et al., 2004). The understanding of ASD is also influenced by the cognitive developmental level of the peers receiving the explanation (Glasberg, 2000). For secondary school students it is anticipated that they would understand the construct of ASD from a physiological perspective, however research has shown that this is not always the case and those without direct contact or
familiarity may have less sophisticated understanding, including cause and effect or even a belief that they could ‘catch’ autism (Campbell et al., 2011; Glasberg, 2000). Campbell and Barger (2011) conducted the first ever study of middle school students’ knowledge of ASD. Some 1,015 middle school students (mean age – 12.95 years) were tested on their knowledge of autism using the knowledge of Autism (KOA) scale. Results show that 53.9% of the sample had no prior knowledge of autism. Overall those with prior knowledge performed significantly better. Despite high percentages of correct answers, gaps in knowledge of autism were identified in terms of chronicity, transmission and aetiology. Incorrect beliefs or knowledge of ASD could lead to students avoiding those with ASD or attributing difference to incorrect causes and impair social acceptance.

Two qualitative studies also showed similar results, with approximately 70% of students being able to give an accurate definition of ASD, but many of the students lacked any in depth understanding of core symptoms or how difficulties may contribute to peers’ difficulty navigating the social environment of school (Campbell et al., 2011; Silton & Fogel, 2012).

### 7.7 Attitude and Intentional Behaviour of Peers

Closely allied to knowledge and awareness are the concepts of attitude and intentional behaviour. These are the factors which will most likely dictate the way in which a peer interacts and behaves towards their peer with ASD. Attitude is defined by Triandis (1971) as “an idea charged with emotion which predisposes a class of actions to a particular class of social situation” (p2). It is believed that positive attitudes motivate more positive social behaviours (Tonnsen & Hahn, 2016). Behavioural intention relates to the conative component of attitude, in other words the student inclination to act.
The definition given by Swaim and Morgan (2001) is “the degree to which children are willing to commit their own behaviour towards acceptance or rejection of a person with a disability” (p.196).

There is evidence in studies of college students that even with quite good and accurate knowledge of ASD, they still maintained a negative attitude or stigmatised those with ASD (Nevill & White, 2011; White, Hillier, Frye, & Makrez, 2016). In essence, knowledge about ASD although a good start is not a predictor of positive attitude (White et al., 2016). Research has also shown that only giving explanatory information or knowledge-based information is not enough to change behaviours and attitudes (Swaim & Morgan, 2001). Campbell et al. (2004) conclude that explanatory information is also needed to change students’ attitudes and perceptions about their peers with ASD. However, giving both descriptive and explanatory information may not be adequate to actualise change in social patterns. For many young people it is also about others’ perception of them, they do not want to be seen by others as someone who associates with those who are different. This raises a challenge for identifying individuals as having ASD within the school setting and potentially re-enforcing difference. Fondelli and Rober (2016) reiterate this point based on their qualitative study of teens and the meaning they ascribe to ASD. For many, whilst they report good knowledge of ASD and positive intentions towards those with ASD, it is the fear of being excluded by being seen to socialise with ‘different’ students that may prevent them actually spending social time with their peers with ASD. This is an argument for whole class and school ASD acceptance programs. It is also true that in many schools those with ‘difference’ or ASD are already identifiable by their segregation from peers for certain classes or activities. It appears that students who know about ASD also need to get to know someone with ASD particularly in the school context. The fear of being
seen to associate with somebody who is different needs to be alleviated for the students (Fondelli & Rober, 2016).

Gender, age and prior knowledge of someone with ASD are presented as the most influential factors in attitude and behavioural intention. Studies of attitude show that girls demonstrate a pattern of more positive attitude to those with ASD when just descriptive information is given (Campbell et al., 2004). Attitude is shown to become more negative with age, this is thought to closely ally with increasing complex social situations and increasing self-awareness (Campbell et al., 2004; Campbell et al., 2011). Previous experience or knowing someone with ASD is also certainly an influencing factor for biomedical knowledge of ASD, but its influence on attitude is less clear (Campbell & Barger, 2011, 2014).

Very little is known about secondary school students’ attitude or behavioural intentions towards their peers with ASD. Campbell and Barger (2011) report 77% of elementary and 46% of middle school children in the US have awareness of the term Autism. A survey of 11 and 16-year-old children in Northern Ireland (n=3343) showed similar results, with 50% and 80% having awareness of autism respectively. Factors closely linked to positive attitudes towards ASD included being female, being ‘autism aware’ and personally knowing someone with ASD. In addition, 16 year olds having experienced a long-term health condition themselves or those with lower economic status were factors in positive attitudes (Dillenburger, Jordan, McKerr, Lloyd, & Schubotz, 2017).

However, levels of awareness or knowledge about ASD do not seem to permeate the experience of school for many students with ASD especially in terms of social acceptance (Humphrey & Hebron, 2015; Humphrey & Symes, 2011). There are more positive outcomes when interventions are used to couple knowledge with peer
experiences and personal contact (Mavropoulou & Sideridis, 2014). Research into improving attitude towards those with an intellectual disability within schools demonstrates that the quality of the contact students experience with each other is most important to changing attitudes (McManus, Feyes, & Saucier, 2010). The few reported programs which aim to improve student knowledge and understanding or reduce stigma towards those with ASD appear to lack this emphasis, with a focus on imparting knowledge and giving a strong anti-stigma message, but without any contact or communication between those with and without ASD (Campbell et al., 2004; Gillespie-Lynch et al., 2015; Ranson & Byrne, 2014; Staniland & Byrne, 2013; Swaim & Morgan, 2001). An extensive review and analysis of peer education programs, their content and outcomes are provided in Chapter 11.

### 7.8 Conclusion

The core social deficits associated with ASD imply that making social connections and getting along with peers is a challenge for students with ASD. There is also a small but growing body of evidence indicating that peers are less likely to engage with those with ASD because of their perceptions of difference and misunderstandings about ASD. This creates a mutually challenging environment for students both with and without ASD to connect. Educating peers about ASD and looking at measures which can reduce stigma and improve awareness shows promising outcomes for addressing this social impasse. However, more evidence of effective methods to achieve this in secondary schools is required.
8 Chapter Eight: Qualitative Study of Parental Perceptions on Transition to Secondary School

8.1 Aims of chapter
This chapter presents a qualitative study carried out to investigate parental perceptions on the transition to secondary school for their child with ASD. It was undertaken in order to give an initial context to further studies carried out in this thesis. Background literature to this study is presented in Chapter 5 and supplemented in the current chapter by an introductory section, followed by methods, results and discussion of findings. The study aimed to interpret findings in a pragmatic way, which may be useful to parents preparing for their child’s transition to secondary school.

8.2 Introduction
The transition to secondary school has been acknowledged as a stressful time for both students and their parents. It is also recognised that for many these stresses alleviate as the student settles into secondary school during their first year (Zeedyk et al., 2003). For students with ASD, the literature reports a somewhat different picture, with students and parents experiencing challenge and stress beyond what would be typically expected (Cadman et al., 2012; Dillon & Underwood, 2012; Kenny, Shevlin, Walsh, & McNeela, 2005; Mandy et al., 2015; Mandy et al., 2016; Mount & Dillon, 2014; Peters & Brooks, 2016).
There are many reported factors associated with a positive transition for students with ASD, relating to characteristics of the school and student, the nature of support and social experiences (Dann, 2011). More negatively, social isolation, bullying and anxiety commonly feature in a student with ASD experience of secondary school (Carrington & Graham, 2001; Humphrey & Lewis, 2008a). Tobin et al. (2012) point out that the transition period is critical to parental perceptions of the function of education for their child.

Parents are reported as playing a key role and directly influencing certain factors in the transition to secondary school for students with ASD (Hughes, 2011; Parsons, Lewis, Davison, et al., 2009; Parsons, Lewis, & Ellins, 2009; Peters & Brooks, 2016; Tobin et al., 2012). School choice is primary in these factors. It is often the role of the parents alone to make the choice as to where their child will go to secondary school (Byrne, 2013; Whitaker, 2007). School choice is known to be influenced by policy and provision in the particular country or jurisdiction (Byrne, 2013). More generally school choice has been linked to ideology, social class and resources, with an overarching parental concern being to find a school which is the right fit for the needs of their child (Byrne, 2013; Parsons, Lewis, Davison, et al., 2009; Runswick-Cole, 2008). The reported challenge for many parents is that they feel unsupported and anxious throughout the process of making school choices (Dillon & Underwood, 2012; Rice et al., 2011; Tobin et al., 2012).

Parsons, Lewis, and Ellins (2009) and Peters and Brooks (2016) demonstrated that an unfulfilled requirement for tailored, individualised assistance or support at the time of the student’s move to secondary school can frustrate or stress a parent. Similarly reported by Byrne (2013) is the frustration of unmet education and information needs when it comes to school choice.
As parents guide and support their child through the transition to secondary school it appears that this stress and anxiety remains present. Dillon and Underwood (2012) report this as being driven by concerns around the need for individualised understanding of their children by the school community and a concern that mainstream schools may lack expertise with students with ASD. Peters and Brooks (2016) explain that parents report a more positive transition when both pre-transition supports and ongoing support in the physical and social environments of secondary school are implemented. Parental concerns around the transition time for their child appear to centre around two main aspects or questions: Will the new school environment lead to social isolation, lack of understanding or a widening of the social gap between their child and other students?, and, will the school staff have the knowledge skills and capacity to educate, support and facilitate their child? (Byrne, 2013; Peters & Brooks, 2016).

A dichotomy emerges in the literature between the views of parents and schools. Parents report a desire for socially inclusive mainstream schools that can cater to the individual child’s needs, where the child would be happy and where they can manage behaviours and differences (Peters & Brooks, 2016; Tobin et al., 2012). Whereas the schools and their personnel appear to have concerns over training and expertise to support teaching and learning for students with ASD, with studies reporting mainstream teachers feel they lack expertise to teach students with ASD (Batten, 2005; Parsons, Lewis, Davison, et al., 2009; Whitaker, 2007). Relating to the concept of inclusion and parental concerns about their child not fitting in or being socially isolated, there is a sense that inclusion in the secondary school environment is a more difficult concept to define and may differ in form and ideology to the primary school environment (Byrne, 2013; Tobin et al., 2012).
Recent studies suggest parents hope that their child be understood as an individual or unique within the school system, whilst also wanting schools to be equipped to understand the challenges of ASD in general (Dillon & Underwood, 2012; Peters & Brooks, 2016). Humphrey and Lewis (2008b) found that having a diagnosis of ASD equated to being labelled as different, causing students to be treated in a certain way by everyone. A label can provide a mechanism for professionals, parents, peers and the student themselves to assume that everyone with ASD be characterised in the same way (Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012).

Educational placement in Ireland is based on a continuum of options. Policy dictates three distinct educational settings: mainstream class in a mainstream school; special class in a mainstream school, and special school. The EPSEN act recommends that students should be in a mainstream school where possible, unless it is not in their best interest or the interest of the other students in the class (2004). This means that the secondary school educational context for students with ASD is typically the mainstream school, with classes ranging from mainstream on a full-time basis to special classes on a full-time basis. Students with ASD are entitled to be allocated a Special Needs Assistant (SNA) to assist with their individual needs (Daly, 2016).

### 8.3 Methods

#### 8.3.1 Purpose and Aim

This study seeks to explore the transition to secondary school and the proceeding period for students with ASD from the perspective of their parents. It aims to gather the parents’ personal accounts of their views of the transition experience for their child and of their perceptions of both the positive and the negative factors inherent in the process of transition. There was also an emphasis on seeking useful information for others from
the parent’s perception, views and choices. The research question involved the following: what is the parent perspective on the transition to secondary school and the proceeding period for their son/daughter with Autism Spectrum Disorder?

8.3.2 Qualitative Research Approach

The focus of qualitative research is on meaning, experience and its interpretation. It aims to discover variables rather than test them as quantitative methods may (Corbin, Strauss, & Strauss, 2014) A qualitative study aims to generate an understanding of the world which the participants inhabit, in this case being a parent of a child with ASD who has moved to secondary school (Braun & Clarke, 2006). Thus, the aim of this study dictates a qualitative approach.

As parents were reporting on their own perceptions and also their child’s experiences, an exploratory descriptive method was required. Thematic analysis offers freedom and flexibility whilst still providing a rich and detailed account of data (Braun & Clarke, 2012). Thematic analysis was used as a pragmatic method to report on the experiences, meanings and the reality of the transition to secondary school from a parent’s perspective. Qualitative research acknowledges this contextual nature of data and also the fact that data are socially mediated around the nature of reality for the participants and the relationship of the researcher to the topic. (Denzin & Lincoln, 2008). Thematic analysis is not associated to any epistemological position but lends itself to a critical realist perspective.

Critical realism views knowledge as socially influenced, it reflects that understanding the ‘truth’ can exist and be shared by a number of individuals. However, each individual’s experience of truth will be influenced by their own subjective construction of that truth. Truths effectively gain weight or saliency by accumulating
evidence (Robson, 2002). Qualitative research is often the first step in exploring a topic or area, this was important to this research as giving later studies context was a key factor in the study.

### 8.3.3 Research Design

The research process is outlined in Figure 8.1

![Figure 8.1. The research processes employed](image)
8.3.4 Participants

Purposive sampling for qualitative research intentionally selects informants that can provide the necessary information and reflect the issues of interest to the study (Denzin & Lincoln, 2008). In this case, inclusion criteria were parents of students with ASD who had already made the transition to secondary school. It is acknowledged that the parents were giving their own view or perspective and not as a proxy for their son or daughter. Following receipt of ethical approval from the School of Psychology, Trinity College Dublin recruitment was initiated through the main organisations and support groups for people with ASD in Ireland. Participants were recruited through a number of ASD support groups and organisations in Ireland, with Irish Autism Action acting as the umbrella group. Parents were also recruited through a parenting website / network, with some snowball sampling as a result of this. Information about the study was disseminated via social media and at a parent support group in Dublin. Parents could contact the researcher to express their interest in the study and they were then provided with participant information sheets, which outlined the purpose of the study. They were then given the opportunity to speak to the researcher about the study and revert with agreement to be interviewed. The participants were therefore self-selected and not random.

There is much debate and little consensus relating to appropriate sample size in qualitative research. As the study did not seek to capture one truth, but more act as an introduction to the area being studied, capturing a depth and breadth was prioritised over reaching saturation in sampling (Corbin et al., 2014). Corbin (2014) also explains that pragmatics and feasibility are important consideration for sample size. As this study was set up as introductory phase to further area of study involving secondary school and
ASD, a large sample size and lengthy data analysis would not have served this purpose (Patton, 2002). Clarke (2013) recommend between six and ten interviews for a small project. Therefore a sample size of eight parents was deemed sufficient for the purpose of this study.

The study included eight parents who represented a diversity in terms of geographic locations and their son / daughters level of ASD (n=8). The interviews happened in a place of convenience for the parent. All participants were given an outline of the interview topics, the opportunity to ask questions and all signed consent prior to the interview taking place. Table 8.1 outlines the participants and their child’s diagnosis.

Table 8.1 *Participant and child characteristics*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Father/Mother</th>
<th>Rural/Urban</th>
<th>Child’s Diagnosis as reported by parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent 1</td>
<td>Father - son</td>
<td>Rural</td>
<td>Asperger’s syndrome</td>
</tr>
<tr>
<td>Parent 2</td>
<td>Mother - son</td>
<td>Rural</td>
<td>*ASD / DCD / ODD</td>
</tr>
<tr>
<td>Parent 3</td>
<td>Mother - daughter</td>
<td>Rural</td>
<td>Asperger’s syndrome / *SPD / eating disorder</td>
</tr>
<tr>
<td>Parent 4</td>
<td>Mother - son</td>
<td>Rural</td>
<td>Asperger’s syndrome</td>
</tr>
<tr>
<td>Parent 5</td>
<td>Mother - son</td>
<td>Urban</td>
<td>*ASD (mild)</td>
</tr>
<tr>
<td>Parent 6</td>
<td>Mother - son</td>
<td>Urban</td>
<td>*ASD (mild) / ODD</td>
</tr>
<tr>
<td>Parent 7</td>
<td>Mother - son</td>
<td>Urban</td>
<td>*Asperger’s / ADHD / DCD / ODD</td>
</tr>
<tr>
<td>Parent 8</td>
<td>Mother - daughter</td>
<td>Urban</td>
<td>*ASD</td>
</tr>
</tbody>
</table>

* Autistic Spectrum Disorder (ASD), Developmental Co-ordination Disorder (DCD), Oppositional Defiant Disorder (ODD), Sensory Processing Disorder (SPD), Attention Deficit Hyperactivity Disorder (ADHD)
8.4 Procedures

All interviews took place in a place of convenience for the parents, these were in their family home (n=1), a community setting (n=4) and the private office space of the researcher (n=3). Interview length ranged between 30 minutes to one and half hours. All interviews were carried out by the researcher in person over a three-month period.

A semi-structured interview format was utilised with open ended questions and probes. The leading questions had been formulated around the literature which looked at factors in the transition to secondary school for students with ASD (Dann, 2011; Dillon & Underwood, 2012; Osborne & Reed, 2011; Rice et al., 2011; Tobin et al., 2012). The questioning started by openly asking the parents to tell their story of their child’s transition, moving onto more specific questions looking at barriers and facilitators, then to a more in-depth discussion about specific factors within the student and the school environment which may have helped or hindered the students settling into secondary school. The schedule allowed parents to speak freely and easily about their experiences, their perceptions of their child’s experiences and of the transition and secondary school experience. Probes included “can you tell me more about….” or “can you give me an example of……”

In order to provide background and contextual information, participants completed a short demographic questionnaire. Table 8.2 presents the demographic and diagnostic information of the participants and their son/daughter. Of note there was only one father interviewed and four of the students were reported as having co-occurring conditions alongside their ASD diagnosis.

Table 8.2 provides the school-based information about the children of participants. This was background information given by the parents in relation to the supports and services their child received and their level of secondary schooling.
Table 8.2 *Child and school information*

<table>
<thead>
<tr>
<th>Child</th>
<th>Child’s secondary school</th>
<th>SNA in school</th>
<th>School year</th>
<th>Resource Teaching</th>
<th>Attend a service for ASD</th>
<th>Support in school from service</th>
<th>Transition management</th>
<th>Primary education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1</td>
<td>fulltime mainstream</td>
<td>not required</td>
<td>2nd year</td>
<td>Not required</td>
<td>no</td>
<td>no</td>
<td>Informal liaison between schools</td>
<td>ASD class in mainstream school</td>
</tr>
<tr>
<td>Child 2</td>
<td>fulltime mainstream</td>
<td>yes</td>
<td>1st year</td>
<td>Yes</td>
<td>no</td>
<td>no</td>
<td>Group and individual programme. Parent led liaison between schools</td>
<td>Mainstream primary – changed school: after initial difficulties.</td>
</tr>
<tr>
<td>Child 3</td>
<td>mainstream and ASD unit</td>
<td>yes – shared depending on need</td>
<td>3rd year</td>
<td>Yes – limited Disability team</td>
<td>no</td>
<td>Group and individual programme. Parent led liaison between schools</td>
<td>Mainstream primary</td>
<td></td>
</tr>
<tr>
<td>Child 4</td>
<td>full time mainstream</td>
<td>yes</td>
<td>1st year</td>
<td>Yes – 8 classes per week</td>
<td>no</td>
<td>no</td>
<td>Group programme. Parent led liaison between schools</td>
<td>Mainstream primary</td>
</tr>
<tr>
<td>Child 5</td>
<td>full time mainstream</td>
<td>yes – shared with one other</td>
<td>2nd year</td>
<td>Yes</td>
<td>no</td>
<td>no</td>
<td>Individual plan and informal liaison between schools</td>
<td>Mainstream primary</td>
</tr>
<tr>
<td>Child</td>
<td>Type of placement</td>
<td>Full time</td>
<td>Year</td>
<td>Yes/No</td>
<td>Occasional psychology and social skills groups</td>
<td>Led by</td>
<td>Mainstream education</td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>----------------------------------------</td>
<td>-----------</td>
<td>--------</td>
<td>--------</td>
<td>-----------------------------------------------</td>
<td>--------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td>Child 6</td>
<td>full time mainstream</td>
<td>yes</td>
<td>3rd year</td>
<td>Yes – 2 classes per week</td>
<td>No</td>
<td>Group programme. Parent led liaison between schools</td>
<td>Mainstream primary</td>
<td></td>
</tr>
<tr>
<td>Child 7</td>
<td>mainstream and ASD unit</td>
<td>yes</td>
<td>1st year</td>
<td>In ASD unit</td>
<td>HSE Occupational Therapist</td>
<td>Group programme</td>
<td>Mainstream primary</td>
<td></td>
</tr>
<tr>
<td>Child 8</td>
<td>mainstream shorter hours</td>
<td>yes</td>
<td>4th year</td>
<td>Yes</td>
<td>no</td>
<td>no</td>
<td>Parent led liaison between schools</td>
<td>Mainstream primary</td>
</tr>
</tbody>
</table>
8.5 Data Analysis

Audiotapes were professionally transcribed verbatim and then listened to by the researcher to ensure accuracy. Preliminary notes, thoughts and observations were made. The transcripts were uploaded to NVivo 10 software. Thematic analysis is a method which identifies, organises and develops insights into themes across a data set and was chosen as the guiding methodology for data analysis (Braun & Clarke, 2012). It allows for making sense of collective experiences and meanings. There are six phases of data analysis as described by Braun and Clarke (2012) which were utilised and are presented below. Coding was data-driven, with themes drawn from all data gathered. Analysis therefore involved a systematic process of coding and theme identification across the data. Phases of data analysis included the following:

Phase 1: Familiarise yourself with the data: This was done through listening to the taped interviews, reading and re-reading the data (once it had been transcribed.) Initial ideas, thoughts and notes were made.

Phase 2: Generating initial codes: Interesting features and commonly occurring points were noted across the data set. This led to an initial coding by highlighting these commonalities and salient points across all the transcribed interviews. These features of the data were all considered pertinent to the research question. The whole data set was given equal attention. Twenty-six codes were identified.

Phase 3: Searching for themes: Listing and re-reading these early codes aided with noting potential themes. Some potential themes at this stage related quite directly to the questions asked of the parents and were viewed as requiring further clarity and active analysis. A strong emphasis on the child, the parent and the school environment were identified at this point. Communication was also a large theme; with many sections of coded text linking directly back to aspects of communication. Any themes which did
not have enough data or where too diverse were discarded or amalgamated back into another theme. It was considered important that the themes would represent a coherent pattern across the whole data set.

Phase 4: *Reviewing the themes:* With early themes identified, closer analysis of the patterns and depth of the data set could happen. Peer de-briefing was used at this point to discuss and map themes in more depth. A dynamic thematic map was developed which took into account the interactions between parent, child and school. These themes also aimed to reflect the concepts of working towards a successful transition and recognition of student potential to attain which parents expressed in many different ways across the data set. The sense of anxiety or concern about student to school fit was also identified as an important factor in the parents reporting of the experience.

Phase 5: *Defining and naming the themes:* On-going analysis allowed the themes to reflect the parents’ story of their child’s transition, with an emphasis on the process and context as well as factors which help or hinder a positive secondary school experience. Each theme needed to be clearly defined and accompanied by detailed analysis. Each theme was also named and described, in a manner which indicated its essence.

Phase 6: *Producing the report:* Writing up the analysis and themes, allowed for revisiting of the coded text to find extracts from the parent’s interviews which illustrated the themes. These extracts or examples from the transcripts where chosen as the most lucid examples of the point being made.

### 8.5.1 Dependability and credibility

Credibility was maximised by using prolonged engagement including attending parent support groups in which some participants were involved, discussing relevant issues with parents whose children were attending secondary school and having an awareness...
of the issues through contact with various agencies and parent groups. Peer debriefing was also utilised with a peer who was an expert in qualitative methods but not in the field, leading to a discussion on interpretations of codes and themes from the data set. Each research participant member checked their interview transcript and summary of the data. One participant raised some queries about her answers and changes were made accordingly. An audit trail was also maintained including notes and processes of data collection and analysis.

8.6 Findings

8.6.1 Description of themes

Participants and their children were labelled using numbers e.g., parent 1 (and where they refer to their child, child 1). The label child was used to refer the parent – child dyad, but it is recognised that the participant’s sons and daughters were in their teenage years, see Tables 8.1 and 8.2.

In exploring parental perceptions of the transition to secondary school and proceeding period for their child with ASD, five major themes were identified through analysis. The parents spoke about: the transition process and its context, the importance of communication for a successful transition, the challenges of social participation for their child, how the individuality of their child and their ASD created specific issues and the many factors for attainment in secondary school which are inextricably linked to unlocking the child’s potential. These themes are listed in Figure 8.2 along with the sub-themes which formulate them.
All eight parents told the story of their child’s transition to secondary school. This allowed the context to be set before further detail and reporting of their perception of their child’s experience. There is diversity to the sub-themes but ultimately they all translated into the child’s transition to secondary school and the parents’ concerns and hopes that the secondary school could deal or manage their child and their differences. These include the important factors considered by the parents for transition, the emotions which they experienced and the practical supports and strategies which were put in place.

### Figure 8.2 Themes and subthemes from data analysis.

| The Transition Process | • factors  
| | • supports and strategies  
| | • emotions and anxiety  
| Communication for Success | • importance of communication  
| | • parents as advocates  
| Social Participation | • desires and challenges  
| | • social connections  
| The Student as an Individual with ASD | • challenges of ASD  
| | • the individual child  
| Factors for Attainment | • ethos and size of school  
| | • factors within the child  
| | • school personnel  
| | • Inclusion  

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### 8.6.2 The transition process

All eight parents told the story of their child’s transition to secondary school. This allowed the context to be set before further detail and reporting of their perception of their child’s experience. There is diversity to the sub-themes but ultimately they all translated into the child’s transition to secondary school and the parents’ concerns and hopes that the secondary school could deal or manage their child and their differences. These include the important factors considered by the parents for transition, the emotions which they experienced and the practical supports and strategies which were put in place.
8.6.2.1 Factors

Four parents spoke at length about the process of choosing a suitable school for their child. They reported that considering their child’s differences in the selection of a suitable school was vital to a positive secondary school experience. For two of the parents this included the facility of an Autism unit or program. These parents considered that specialism in Autism was a way of ensuring the school could manage their child.

*We decided on his school, we visited his school three times over three years. I visited nine schools between fourth and sixth class, before we decided which one he would like. The school is out of the area, it’s thirty kilometres away.* (parent 3)

*So we chose this school with an autistic unit in it for her and we felt that they would cope with some of the problems that she had.* (parent 4)

The other parents based their decision of which school to send their child to on factors such as locality or following in the path of siblings.

*We wanted her to have what her sisters had.* (parent 8)

One parent spoke about initially sending their child to the school his brother went to, and quickly realising it did not suit their son with ASD

*...we actually started him in my son’s school but there’s no learning support, no acknowledgement of a difficulty at all so we just took him out because it was ridiculous, like he stopped talking, he was wetting the bed, there was no question but that it was the wrong school for him. Perfect school for my other boy....*(parent 5)
Two parents had thought about accessing special education, but in the end opted for mainstream schools with experience of ASD.

For him you know now if you do get him into a special school he may be fine for the first few weeks and then start having meltdowns and I tell you it’s the best thing that we never done it, we left him where he was. (parent 7)

Outside agencies, such as educational psychologists, SENOS or ASD services featured in very few parents reporting of the transition process, but where they did parents found it useful.

…he was going into a school, a mixed school of seven hundred plus children where the record wasn’t entirely what it should be as regards ASD children. We had known that from two previous students coming from the same school, but we were kind of adamant that they would come up to speed, as was the local SENO who played a huge part in the whole process. (parent 2)

With most parents feeling they ultimately made the decision about what school to send their child to alone.

…like I mean when I asked the primary school where do you recommend I send (my son), “God I don’t know”, now that was from the principal… (parent 5)

The parents described how they needed to organise a lot of reports for the secondary school so that resources would be in place by the time their child started.

The transition did require a lot of work…a lot of reports… there was a lot of background work to do. (parent 8)

Very few of the children had any kind of formal transition planning. Those parents that reported it perceived it to have been useful for their son or daughter.
The parents spoke about the many practical ways their child’s transition had been managed. Many of the strategies came directly through the parents instigating communications and setting up plans for their children prior to commencing secondary school. Often the parent’s initiation of a strategy was taken up by the school and worked successfully to manage the change for the child. All of these strategies were about the schools dealing with the students ASD and how it presented itself as a barrier to participation.

*I suppose we came up with a few vital steps that made the transition a lot easier in our own, just in our own, this was kind of our own idea, the school’s idea and the NEPS psychologist’s idea. It was always our intention as parents that he would see the school and become familiar with the school. (parent 1)*

Strategies included communicating behavioural profiles of their child, colour coding text books, making visual maps and reference to the school and arranging meetings with other students from the school.

*We handed over a list of dos and don’ts, like that they had it set-up so that when CHILD 2 came in, because there’s a bank of lockers, that he wasn’t going to get the locker in the middle, you know what I mean. There was colour coding, they even put colours, squares on the door, he doesn’t even need them now, you know, so this was Maths was blue or Science was red or whatever and he got to meander around the school as sort of, well a guided tour not a meander, a guided tour of the school so he knew where the different rooms were, knew were to go when it was empty. He then as, as I say, the colour coding went onto his books as well, they also had a day where all the children, all the First Years*
came into school and they had their lunch, etc. and they tested every subject, which I thought was a great idea. So they did a little bit of woodwork, a little bit of metalwork and he brought home a key ring with his thumbprint on it and things like this. (parent 2)

siblings were often referred to as useful supporters of the transition process, specifically for the social aspect of school, which parents believed would create problems for their child with ASD. They could show their younger sibling the how’s and why’s of secondary school and prepare them in an age appropriate way.

Now his older brother, whom he idolized, had just left the school but had him well tutored as well. (parent 1)

And he was asking his older brother because he done it and he was telling him all about it, so he thinks he’ll never get back to school to do all this. (parent 7)

the parents were very clear, about their perceived role as an advocate and voice for their child during the transition as being a vital part of the process. They advocated for their child’s differences and challenges within the mainstream.

So I had this group of people all meeting up and we were sitting, and I also had CHILD 2’s resource teachers that he had in primary as well, sorry, and me, the advocate I call it. (parent 2)

No. I mean any plan that’s kind of worked, and I’m not blowing my own trumpet by any means, I’ve had to kind of tell them to do it. (parent 5)
Many strategies and supports were implemented by the secondary schools, which the
parents reported on. Often these supports came about due to collaboration between the
parents and the school. There were many different types of strategies and supports
mentioned including school visits, fact files, and allocation of resource hours, quiet
areas and Special Needs Assistants.

*I suppose ourselves, the school, the primary school and the two teachers in the
unit came up with this idea of a simple fact file about CHILD 1 a picture, a two
page fact file, just about CHILD 1, his diagnosis, the dos and don’ts in a bullet
point presentation, what may freak CHILD 1 out, what CHILD 1 may answer to
in a certain situation, not to misinterpret what he might say because of a mode
of, a direct answering mode which he sometimes employs because of his
diagnosis, not to misinterpret it and that it was vital for every teacher in the
school just to read this simple two page fact file, this is CHILD 1, this is his
diagnosis and this is what may happen and this is how to interpret it. (parent 1)*

*But one of the best things in the school is they have a sensory room so when she
gets overloaded down she goes. (parent 3)*

*he’ll be using a tablet or a small laptop at school from September apart from his
Maths and his handwriting is so bad his teacher wants him to have a scribe.
(parent 4)*
8.6.2.3 Emotions and anxiety

All eight parents referred to feelings of anxiety and worry prior to the transition. They mainly referred to their own worry but also to that of their son or daughter. For many once their child had settled into school, they reported alleviation of their anxiety, and for some relief at the success of the transition. The worry or anxiety was often expressed in a general way, but for some they could pin point to the difficulties they perceived having ASD would bring their child in a secondary school environment.

*Because I had been worried for so long, wondering what on earth is going to happen to him when he leaves the school that he’s loved for eight years, you know, and to send him to a school where he knew nobody.* (parent 3)

*I was petrified.* (parent 4)

*I was praying because that’s all you’ve got left at this stage. You know, sometimes, I was praying that he’d get a good SNA….(parent 1)*

Parents also referred to wanting their child to be happy and settled in secondary school. Seeing and hearing that their child was happy and settled gave parents obvious satisfaction.

*You are happy with your child if your child is happy.* (parent 8)

8.6.3 Communication for Success

8.6.3.1 Importance of communication

Communication was an important aspect of the transition process for the parents. Ultimately lines of communication between the school and home allowed the parents to understand how their child had settled into secondary school. Parents referred to both positive and negative experiences of communication. Overall good communication
appeared to represent alleviation of many of the parents expressed anxiety about the ‘great unknown’ of secondary school.

   Examples where given of how communication between primary and secondary schools had eased the transition journey.

   But I was talking to Mr TEACHER is his name, he actually looks after him in the unit and he was saying to me like, he rang me just before they finished and he just said to me the difference in him between Christmas up to now. (parent 7)

   I think, the other thing they do is that every year in June we meet, sometimes with him, sometimes without him, depending on the humour at the time, where we go over what was good during the year, what was bad and what we can try to do for the next year and at the end of First Year she said to me, right what are we looking for now for Junior Cert, so two years ahead. (parent 4)

Frustration was expressed where communication had broken down and children had become unhappy or distressed.

   Yeah but they didn’t communicate and I saw his journal and I thought well, because she does pull back and he does write his stuff, even if it’s spidery and all over the place, but there wasn’t even homework written in on some of the things so I was kind of – and why didn’t somebody tell me, you know, he had to go a couple of weeks, he was becoming like a demon. (parent 2)

   Yeah, or being watched, there’s nowhere near the level of observation in secondary that there was in primary, do you know, and I was a bit kind of disappointed at that. I kind of expected people to, oh can I have a word, outside
the school, and is that your boy, oh he's getting on great, and blah, blah, blah.

And they had a school chaplain, she's since gone, but she says, “God he's a lovely boy, Michael * isn’t it” I thought Jesus Christ, Michael, Michael. (parent 5)

*this is not the child’s name – chaplain was referring to a different child in error

Parents also spoke about how their children’s weaker communication skills meant that communications from school were very important to them.

So that diary was there and what is absolutely excellent, and I really like this is that they had a system of, you know, looking for the good so if she was in her Maths and was doing very well today in Maths she opens up this good notes page and they put great participation in Maths today or well done and signed. (parent 3)

Often communication was quite formal in the form of meetings and appointments. But it was the informal communications which parents seemed to value the most. Some parents reported they had these informal opportunities, whilst others found initiating informal communications a challenge.

the teacher that looks after him has often rang me or I’ve gone down and he’s often said to me like has anything happened, did anything happen last night, now they work with me with him at home and everything. (parent 7)

I know I can ring them anytime. (parent 8)
They do one parent teacher meeting and there were a couple that we just weren’t happy with the ways things were going, but there’s, when you try and work with it, you know, you don’t get any answer. (parent 6)

Parents advised that keeping lines of communication open between school and home was vital to the secondary school experience for their child, especially when things had gone wrong for their child. Advice was also given about being open and honest with the school from the start.

Yeah, but generally absolutely no problem at all, but they knew in advance what they were dealing with and I think, you know, if parents are upfront and say this is what we’re dealing with here and this is what we’re going to need then that’s fine. I think it might be a bit different if I just sort of squished him in. (parent 4)

The role of Special Needs Assistants in communicating with home appeared to be important to the parents, especially for more informal feedback or messaging between home and school. Generally, any communications acted as a reassurance to parents.

8.6.3.2 Parents as advocates

All the parents referred to their roles as an advocate for their child. Many expressed strongly that they believed they had to work in the background to support their child getting on in secondary school and ensuring that they were getting fairly treated and included within the school. They often had to communicate on behalf of their child.

But you kind of have to be like this to get what you want for your child, not even what you want, what the child needs, you know, and you’re not asking for, you
know, a throne for the child to sit on, you're just asking for the help they need.

(parent 5)

8.6.4 Social Participation

8.6.4.1 Desires and challenges

The parents all spoke about social participation. Many referred to their child’s desire to make social connections but the difficulties they had experienced with this.

Socially she would like to be much more involved and engaged but it doesn’t happen easily. (parent3)

The challenge of socialising for the children was spoken about. Parents acknowledged the challenge of assisting children to socialise within the secondary school environment.

He needs assistance in the socializing which doesn’t, which is a very difficult one to do, which doesn’t stigmatize him, which doesn’t make him feel like he's a total, because he's very conscious of being different and he doesn’t want to be different but he definitely needs a little bit more assistance within the school environment to socialize and communicate, to encourage that. (parent 2)

Parents also referred to their child’s desire to make friends and to be like ‘everyone else’.

He wants to be like everybody else and you get periods of frustration where he might get very upset because he knows he's not got invites, he knows he's going to be last on the team, he knows, you know, there's certain things and that upsets him. (parent 2)
8.6.4.2 Social connections

Some children were reported to have had very positive social experiences and this was often attributed to making social connections through extracurricular activities and interests.

That's it and I think his music has helped him so, so, much because I think without that he would be just a quirky kid who might not be terribly outgoing and friendly but because he had a guitar and I always said to him a boy with a guitar will never be alone. (parent 4)

He hasn't invited anybody back, he hasn't been invited anywhere but he doesn't lend himself to want to, but having said that now I let him bring in his iPod with him and initially I thought oh well, no it lets him chill out. It's so stressful for him trying to be calm and quiet and keep still in class that if he has this at lunchtime he can just zone out from everything else and just bring himself down a wee bit. Then they're playing games in it and he's talking to other kids or showing the games, that was brilliant, this is a link in and there was a couple of kids that he's been sort of, names have been bandied about. (parent 6)

Two of the parents remarked on how their child was aware of their own differences and this could further isolate them. Examples were shared of incidences when their child had got upset or anxious because of this.

She goes through stages where she's very conscious of her difficulties and she gets very depressed and very withdrawn and she would cry in her bedroom and,
you know, I've no friends and I can't make friends and I wish I didn't have this autism or whatever and the rest of it. (parent 3)

Many of the parents spoke about siblings being a useful social ally, but how they also sometimes highlighted the social differences between them.

And in comparison to her brother, who's just the one year older and he's very good with her, she has no life in comparison to him……and then there's a nine year old brother and now she sees the nine year old brother is passing her out.

(parent 3)

Two parents referred to peer mentoring or buddy systems as a useful way of supporting social participation. None of the children had been offered this type of support.

8.6.5 The Child as an individual with ASD

The heterogeneity of ASD in often noted, and the parents spoke at length about their children’s individual differences alongside and the challenges of having ASD in secondary school. Despite the obvious individuality of the children many similar issues where raised.

8.6.5.1 Challenges of ASD

All the parents discussed the importance of routine and schedules to their children. Changes in routine challenged the students. Parents mentioned difficulties with timetables, half days and school holidays.

Do you know it's like Ground Hog Day, every day has to be the same day with him, even at the weekends, do you know what I mean. (parent 7)
Linked to this was a struggle for many students with self-directed, individual study and doing homework.

*What happened was he has decided if, there is no point in studying because if you were in the class you would learn it, why should he read the same thing again because he knows it, do you know, this is his attitude and I said well what if we missed something, you have to do new parts there, you know, it’s really hard.* (parent 2)

Many of the parents gave examples of how their child’s difficulties with language and literal interpretation of instructions had caused issues within school and exam setting.

*Suggest four ways, even in History, suggest four ways of such a thing. CHILD 3 you didn’t do that, well I only needed three, oh right but you had to write down three, but it said four………… *(parent 3)*

Some parents were concerned that this may put their child at a disadvantage in state exams.

*What threw her off was the exam booklet to write your answers in was blue, she never had written on blue paper before, it was always white, I didn’t know if it was right, she said.* (parent 3)

Food and school lunches were another concern for many of the parents. Some of the children had issues with food which meant that they were not eating anything from the school canteen.
Poor understanding of social rules and seeing others’ perspectives was also highlighted by many parents.

*His verbal skills are very good but his comprehension of the social rules and his understanding, his understanding and comprehension of social rules isn’t that great.* (parent 6)

### 8.6.5.2 The individual child

The parents also pointed out that their children were individuals also transitioning to adolescence and acting like ‘typical teenagers’. Some parents referred to the difficulties of separating the child from the ASD for the school.

*And that teacher also said, well I encourage teachers to push him, to challenge him to, like you know, I mean if you don’t try you won't know kind of thing, and he said, well I don’t like to shout at him because of the Asperger’s.* (parent 1)

*Do you know what I mean, he didn’t think there was a problem, he was a few minutes late and like he has to understand, they can’t have one rule for all the kids and a different rule for him.* (parent 7)

Other issues included sensory, organisational skills, time management and handwriting. The parents expressed how many of these issues impacted on their child’s learning and progress in school.

*Child 2 can't write properly, well he has the functions of writing but it is so painfully slow and spidery and it's like so laboured.* (parent 2)
The parents reported on the child’s anxiety. They referenced how anxiety could impact on their child’s behaviour in school. Some parents attributed the anxiety to the pressures of social participation in school. Others spoke about it in a more generalised way in relation to the change in schools.

\begin{quote}
It’s very difficult to get CHILD 6 to join in with other children he doesn’t know, he gets, it looks like he's being really rattty but he's actually feeling really anxious and it looks like he's really cold and like looking up and down but he just, he isn’t, he's just anxious. So they didn’t really, it was hard for them to take that on board because he doesn’t give you anything, you know, it's hard for them. (parent 6)
\end{quote}

Ultimately the child’s happiness was important to the parents and in many ways their happiness in school was determined by the individual child fitting into the school environment. Challenging behaviours and negative emotions were associated with high stress and pressure, whilst the parents reported the children to be happier when they were included and understood.

\begin{quote}
It was terrible really, that was the low point, they were pushing her and pushing her. She couldn’t say ‘excuse me, I’m not able to do this.’ (parent 8)
\end{quote}

\subsection{Factors for attainment}

Once the child had made the transition to secondary school, the parents pointed out and discussed many factors which impacted on their child’s attainment and inclusion in secondary school.
8.6.6.1 Ethos and size

Parents observed how the general school ethos appeared to contribute or hinder their child’s secondary school experience.

So they're very, very business like, they're very academic focused, they're quite exam focused, which is fantastic in the sense that they are pushing her to the best of her academic ability, they are striving for excellence with her, they're taking no second best from her at all so she's working to the very best of her ability and it's amazing the difference in her that is going to stand to her on the long run, do you know what I mean. (parent 3)

But I don’t think special needs children are high up on their list at all.

(parent 5)

The size and number of students in the school was also mentioned by many as a factor which their children had to deal with.

So he went to school and when he started of course there was two hundred and sixty, so this is a massive environment. He couldn't cope, things like, and they had an electronic bell and he went mental. (parent 1)

The fact that I think he was in, now the class wasn’t very big that he was in but it was still very daunting I think for him. (parent 7)

8.6.6.2 Factors within the child

The parents recognised that their child’s characteristics and behaviour also played a part in how they progressed.
I think it depends on her mood, if she's in one of those down moods I can get nowhere, absolutely nowhere, and if she gets into this idea that she is no good and that she is hopeless and she looks terrible, you can't get her out of the bed, you can't get her out of the bed. (parent 3)

And I have to say he’s very well to get on with like, do you know what I mean, he wouldn’t be cheeky or, now he can have his odd moments and that but he’s, like anyone I’ve spoken to, any teachers or anything, like they’ve said to me like he’s a credit, like he’s very well-mannered and you never get any back chat from him and I think that’s what they were expecting. (parent 7)

8.6.6.3 School personnel

Parents referred to school personnel in secondary school environment and the shift from dealing with small numbers in primary school to the multiple numbers of school personnel in secondary school.

Many parents spoke about the challenge of having school personnel and specifically teachers understand their child and the nature of ASD.

So that’s why I said, no more than any other job, some people get it and some people don’t and if you meet the teachers that understand it you're flying and if you don’t you're up against a hill really. (parent 3)

They just get it, you make eye contact and you just know and others are just sort of a bit fazed. (parent 6)
There was a fine line between understanding the child and letting the child away with behaviours because of their ‘special needs’. Some parents spoke about how their child may have been let away with things because of ASD, whilst another reported they had been pushed too hard.

Parents were keen for school staff to understand their child’s potential and drive them towards meeting it. Closely allied to this was being aware of ASD and how best to communicate with and deal with the child and their behaviours.

*So they don’t chase him. Yeah, that’s it and, you know, they’re quite willing to let him, because he’s smart and because he does well, they’re kind of thinking, you know, he will turn it in, and he won’t.* (parent 6)

*I had a parent teacher meeting and nine out of ten teachers said they were waiting for work and I’m like, I know he’s lovely and I know he’s polite and I know he’s wonderful but don’t give him any leeway, where they were like ah but he’s been so good.* (parent 4)

Some parents pointed out that respect was an important aspect to this for their children.

*Respect is very important, and she likes to be treated well.* (parent 3)

For the children who had Special Needs Assistants (SNAs) allocated to them, the secondary school environment changed the dynamic of how the SNA worked with the child. Some parents reported that their child did not want the SNA drawing attention to them and were happier without their help. Whilst others reported that the SNA was vital to their child’s participation in school.
He had an SNA available to him in the school for the first couple of weeks and he said to me, Daddy this blondie girl keeps coming over to me asking me how I'm doing, and I said ah yeah she's just there to help everybody, to see is everybody, yeah but why does she come to me, I said maybe she fancies you. (parent 1)

So respect is hugely important and he respects the SNA and like that she's not Velcroed to CHILD 2 and it's very important that she pulls back, she makes him responsible for certain things. (parent 2)

One parent pointed out that she believed it is important for teachers not to compare children with ASD to the norm or feel sorry for them.

It’s a lot harder with ASD, people are very aware and sort of feel sorry for them. (parent 8)

8.6.6.4 Inclusion

For those children who were in ASD units or resource groupings. Parents were keen that their children were also included in school life. The dichotomy between special classes or units and mainstream school was recognised as a challenge for many children and parents. Whilst it was reported by many that their child required specialist service, they also wanted their needs to be met by the mainstream school.

They kind of just group all the special needs children together and say, oh he's one of them, do you know what I mean, that’s the impression I get now. (parent 5)
And some areas are very good, like just for example he's doing very well in Metalwork and one of the reasons is the way the Metalwork teacher has set them up with little groups, so they're working like, you know, even though they're all doing their pieces and he gets to do everything that he has to do in Metalwork, he's never isolated, he's not made feel different because the whole class is done. (parent 2)

We didn’t want her to be on her own all the time. (parent 8)

Another parent spoke about how sometimes she felt children with special needs were grouped together and they were not dealt with at the level of individual needs.

He took learning support as one of his options and we thought this was going to be teaching him organizational skills, teaching him time management, maybe typing skills, all these things, it's more a babysitting class because it's oh I watched a movie and we got Mars bars. (parent 6)

Overall parents expressed a desire for school personnel to be able to understand their children enough so that they could get the best out of their children and facilitate them to reach their potential, whilst still being able to deal with the challenges that ASD may bring.
<table>
<thead>
<tr>
<th>Top 25 Suggested Strategies by Parents</th>
<th>Parent number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involv the local SENO (Special Educational Needs Officer) and services where possible.</td>
<td>1,2,5,7,8</td>
</tr>
<tr>
<td>Start looking and visiting schools as soon as possible and have an open mind to school options.</td>
<td>1,2,3,4,5,6,7,8</td>
</tr>
<tr>
<td>Consider whether a school with an Autism Class may be appropriate.</td>
<td>3,7,8</td>
</tr>
<tr>
<td>Look at the learning resource room and check if there is a sensory room or break out space.</td>
<td>2,4,5,6,8</td>
</tr>
<tr>
<td>Talk to other parents.</td>
<td>1,3,4,5,6</td>
</tr>
<tr>
<td>Create a link with the new secondary school as early as possible.</td>
<td>1,2,5,6</td>
</tr>
<tr>
<td>Ask about the school’s experience of students with autism.</td>
<td>1,3,4,6</td>
</tr>
<tr>
<td>Familiarise student with school e.g., visit during the summer.</td>
<td>1,2,3,4,5,6,7,8</td>
</tr>
<tr>
<td>Prepare the ground with information about the student for the school e.g., student profile, do’s and don'ts list and professional reports.</td>
<td>1,2,3,5,8</td>
</tr>
<tr>
<td>Implement organisational strategies e.g., colour codebooks, use phone reminders, take photographs of school and teachers, use cue cards.</td>
<td>1,2,3,4,5,6,8</td>
</tr>
<tr>
<td>Work with the school to support time management and time tables</td>
<td>1,2,4,5,7</td>
</tr>
<tr>
<td>Watch out for Autism specific difficulties with language e.g., literal interpretation of questions</td>
<td>2,4,5</td>
</tr>
<tr>
<td>Work with school about schedules for homework and study. The expectations or outcomes of study need to be explicit.</td>
<td>4,5,6</td>
</tr>
<tr>
<td>Organise a meeting with parents, services and school.</td>
<td>1,2,3,4,5,6,7,8,</td>
</tr>
<tr>
<td>Print school rules and familiarise student with them over the summer.</td>
<td>1,3,4</td>
</tr>
<tr>
<td>Embrace technology.</td>
<td>3,6,7</td>
</tr>
<tr>
<td>Create a portfolio of their work and list of their strengths for new school.</td>
<td>1,2,4</td>
</tr>
<tr>
<td>Find a buddy / older student / sibling who can run through how the schools works, nuances and social rules with the student.</td>
<td>1,4,5,7,8</td>
</tr>
</tbody>
</table>
Offer to speak with teachers. 1,2,3,4,5,6,7,8
Keep communication open between school and home, ask for and arrange regular feedback. 1,2,3,4,5,6,7,8
Allow some leeway and explore all available accommodations with the school. 2,3,4,6,7
Be prepared to advocate for your child, don’t be afraid to speak up and pursue things for your child. 2,3,4,6,7,8
Talk to and listen to your child about school. 1,2,4,7
Encourage extracurricular activities – especially music. 1,3,4,5,7
Respect, acknowledge and appreciate the teachers’ time and efforts. 1,2,5,8

8.7 Discussion

The transition to secondary school is recognised as a significant life event (Anderson, Jacobs, Schramm, & Splittergerber, 2000). The success of the transition and the subsequent settling in and participation in secondary school is acknowledged as shaping future educational and social-emotional outcomes (Anderson et al., 2000; Galton, 2000; Zeedyk et al., 2003). The additional factor of having a diagnosis of ASD and the accompanying difficulties inherent to this diagnosis matched with the new experience of secondary school and emerging adolescence makes it increasingly challenging (Connell, Hutnick, Glover, & Glover, 2012; Dillon & Underwood, 2012; Jindal-Snape et al., 2006; Tobin et al., 2012).

This study examined a small sample of parents’ experience of this transition and subsequent participation of their son or daughter with ASD in secondary school. It aimed to elicit some of the key factors for a smooth transition from a parental perspective and also give some insight into the secondary school experience for students
with ASD from their parents’ perspective. The implications of the factors or themes raised by the parents will be discussed here.

It is acknowledged that making a decision about where your child should go to secondary school is often more stressful and difficult when you have a child with any type of additional need (Byrne, 2013). Parents of children with SEN are reported to be influenced in the choice of school by numerous factors both related to the child, the school and the wider social and cultural context (Bagley et al., 2001; Byrne, 2013). The parents in this study represented this by their stories of making the choice about where to send their child to secondary school being varied and influenced by many factors. The common factor was that all choices were presented in the context of concern or anxiety on behalf of the parent that their child would be managed according to their needs or that the school would be able to cope with the differences their son / daughter presented with. Primary education experiences varied within the group but were described in a formative capacity for all children. There is some reference to this in by Byrne (2013) which indicates that a child’s primary school experience will directly influence a parent’s choices for secondary school. Research appears to indicate that a poor primary school experience is more likely to influence parents into considering special education for the secondary school years (Whitaker, 2007). Dillon and Underwood (2012) noted this in their study of parental perspectives also.

All parents described a variety of support and strategies which had been put in place for their child. The ad hoc nature of this was noted. Strategies depended on the parties involved, the parent’s input, school’s expertise and interest. Many of the strategies were those considered ‘good’ practice for students with ASD such as visual systems and home-school communication diaries. There was a noticeable absence of support for social skills or strategies for making social connections, one of the areas
many parents remained concerned about. To date, much of the literature focuses on this concern also, with studies reporting higher incidence of bullying and loneliness for children with ASD in secondary schools (Fink, Deighton, Humphrey, & Wolpert, 2015; Humphrey, 2008; Humphrey & Symes, 2010a; Lasgaard et al., 2010; Locke et al., 2010; Roekel, Scholte, & Didden, 2010; Symes & Humphrey, 2010). None of the parents in this study mentioned bullying or their children being the victims of bullying. Locke et al. (2010) study confirms that adolescents with ASD are significantly lonelier than their peers with the increasingly complex social networks of adolescence and secondary school contributing to their difficulties in making social connections.

Anxiety was expressed by all the parents. This anxiety seemed to weave its way through much of the parents’ descriptions. But it was most readily articulated by them in reference to the first few weeks of school. It is known that anxiety is somewhat normal at this time (Zeedyk et al., 2003). But the extent and manner in which it was presented by this group of parents, implies a real sense of unease about whether schools were competent in dealing with their children and an acknowledgment that a student to school mismatch or fit could have stressful consequences for the child and family (Cadman et al., 2012; Dillon & Underwood, 2012; Kenny et al., 2005; Mount & Dillon, 2014). One of the ways the parents in this study and in other similar studies reported that this anxiety could be alleviated was through effective communications between school and home. Communications were highlighted as important by all the parents. The communication difficulties that students with autism have, often means that parents are reliant on others to communicate on their behalf. The move to secondary school and the change in communications styles from the more informal primary school environment came as a challenge to some of the parents. There was a sense that without communication from the school the parents would have great difficulty knowing how
their child was getting on. Living day to day without really knowing if their child had settled was a source of anxiety for the parents. Simple and frequent communications alleviated this for them. All studies which include parental perspectives touch on this (Dann, 2011; Dillon & Underwood, 2012; Jindal-Snape et al., 2006; Tobin et al., 2012; Whitaker, 2007).

Despite differences in the children’s schooling and their support requirements, all the parents reported that they had a role as advocates or as a voice for their child. This appeared to come from a sense that there were and would be plenty of instances that their child would need a voice or someone to stand up for their rights within the school setting. Ryan and Cole (2009) report similar findings from a large qualitative study of mothers of children with ASD, the mothers in this study similarly presented with motivation to give their children the best possible opportunities.

Parents were very clear to separate their children as individuals from the ASD label that they had be given. The nature of ASD means that despite differences and levels, there is a commonality to the types of difficulties students present with in the school environment (Ashburner et al., 2010; Humphrey, 2008; Odom et al., 2014). Parents were often ambivalent towards the label of ASD preferring their children to be understood as individuals. Conversely it did appear important to many of the parents that ASD was understood and appreciated by the schools. This appears to be a challenge for many, as although parents didn’t want ASD used as the excuse for certain behaviours or quality of academic work, it was also acknowledged that differences and difficulties associated with ASD impact on participation in the secondary school environment. This point is acknowledged by Dillon and Underwood (2012) in their study of parental perspectives, with a key finding that support for students transitioning to secondary school should be tailor-made and individualised. Despite this
heterogeneity within ASD and acknowledgement of each child’s individuality, the main concern for most parent stems from the differences presented by the nature of ASD, namely the challenge of socialising and making social connections within the school.

Parents were eager to point out that for many of the children the desire to make social connections was very strong, the obstacle for most was their difficulties in instigating or participating in social activities. For some their obvious differences in social skills and behaviours left them isolated and without social connections, whilst for others they had managed to cross the boundary through shared interests and groupings. It is recognised that social connections are an important part of school life for all children with and with ASD (Carter et al., 2014). Secondary school students with ASD have also identified their desire to make social connections (Humphrey & Symes, 2010a).

Ultimately all the parents referred to a desire for their child to thrive and attain within the secondary school environment. Levels and markers for attainment varied from happiness to exam grades. Parents recounting of their experiences from their son / daughter’s perspective lead to the identification of many factors which could help or hinder these attainments. With the small sample size and the multiple factors at play in each child’s experience, it seems an impossible task to link or list these. However, some factors did appear to have a commonality and were raised by parents at various points. All parents recognised that the ethos of the school would influence their child’s experience, with some carefully choosing school with an ethos which they believed would allow their child to flourish. Others recognised the issues such as a lack of experience with ASD, or large numbers of students as being potentially negative factors in their child’s experience. For some practical factors such as siblings in the school or locality were more important in decision making than ethos and size. Parents recognised
that they had to deal with potential negative factors in a practical hands-on fashion. This finding is similar to Runswick-Cole (2008), where parental views on school choice were complex and influenced by multiple factors. Certainly, many of the factors the authors identify such as school and class size, presence of other with learning needs and teacher experience are identified as important factors in attainment for students with ASD in secondary school (Osborne & Reed, 2011). It is recognised that the ethos of the school impacts directly on practices of inclusion also (Humphrey, 2008)

Linked to the notion of separating the child from the diagnosis of ASD, parents reported that certain within child factors where influential in how they attained and got on in the school environment. Moodiness and motivation were viewed as influencing the children’s participation. The notion of the child being ‘no trouble’ versus those who presented more of a behavioural challenge to teachers and school staff also emerged. The themes of behavioural and emotional challenges of students with ASD and their impact on school and educational attainments was recognised as being an important factor to school engagement and participation (Ashburner et al., 2010; Osborne & Reed, 2011). Mood, motivation and engagement with school were also recognised factors for all children in influencing their participation and attainment in secondary education, emphasising the point that the ASD label is not the sole contributing factor to a child’s experience, although it may well become the focus (Vaz et al., 2015; Vaz et al., 2014).

Parents were often able to identify one or two members of school staff who were particularly supportive or helpful. Contrary to this, parents also reported that there was an on-going issue in school personnel recognising their child’s needs and working with them to facilitate attainments. Many reported experiencing a lack of understanding about ASD as being central to some of the difficulties children experienced in the classroom. Others reported that their children were being singled out as different and
perhaps even being ‘felt sorry for’ without any expectations being put on them for attainment and progress. Grandin (2006) emphasises this point from a personal perspective, highlighting the importance of teachers who motivate and understand.

Research is beginning to demonstrate a link between teacher skills, knowledge and attitude towards students with ASD and the attainments of pupils with ASD in mainstream schools, with recommendations for more focussed teacher training (Chung et al., 2015; Gregor & Campbell, 2001; Robertson et al., 2003; Symes & Humphrey, 2011a)

Parents referred to the concept of inclusion through recounting stories of when their child was excluded or by giving examples of inclusion. All the parents valued the concept of being part of the school community for their child. With the concept of inclusion being examined under the four-pronged system by Booth and Ainscow (2000) (and represented by Humphrey, 2008), there are many examples of students experiencing a lack of inclusion.

**8.8 Limitations**

This was a limited qualitative study with a self - selected group of eight parents, and an underrepresentation of fathers. However, the sample were a diverse group relating to demographics, types of schools and levels of ASD. It is acknowledged that parents form only one perspective of the experience and their views are both time and context dependent. However, it was felt they would be able to give ideas and information to inform further research in the areas which would involve other stakeholders. As such, the study was a rich source of information to build from in terms of issues, concepts and experiences for students with ASD attending Irish secondary schools.
8.9 Conclusion and Recommendations

The current study shows that parents’ experiences of their child with ASD’s transition to secondary school, was an important factor that they were concerned about both generally and specifically, relating to their child’s ASD and the consequences this may have in the secondary school environment. The participating parents described a mixture of supports and strategies but were unanimous in their emphasis on the importance of communication from the school directly to them. They described communications between school and home as often being less than those they had experienced from primary school and a determination to advocate and represent their children to the secondary school systems. The parents also emphasised their concerns about secondary schools not fully understanding the nature of ASD, and the impact this can have on the child as an individual. Despite differing perceptions and views on the purpose or end product of secondary educations for their child, all of the parents communicated a desire for their child to reach their potential and make progression within the secondary school system. Even within this small sample this study highlights both the heterogeneity of ASD and the different individual needs and behaviours of the children with ASD, but also the need for secondary education systems to more effectively support students with ASD and their families through an understanding of how ASD can impact on school life and participation. Similar to previous research findings stressing the importance of communication, support and understanding the individual, it is clear that parents would benefit from practical and emotional support during this time (Tobin et al., 2012). This study also highlights the need to better understand how children with ASD can be supported for educational and social attainment within mainstream secondary schools in Ireland.

9.1 Introduction

Following on from the parental perspectives reported in Chapter 8, it ensues that a closer examination of the experience of secondary school for students with ASD in an Irish context would be of interest. Research into the secondary school experiences of students with ASD is more limited than primary and early years (Hebron, 2017b). But the studies which have been carried out allude to a number of challenges the students may face in relation to their ASD and their new physical and social environment (e.g., Dillon, Underwood, & Freemantle, 2016; Saggers, 2015). Studies on the transition to secondary school, which are predominately qualitative and UK-based, identify some negative experiences for students (Makin et al., 2017). Students with autism experience difficulties adjusting to their new environment and peer group (Dillon & Underwood, 2012; Tobin et al., 2012). Students themselves also report pressure to fit in, and feelings of difference (Humphrey & Lewis, 2008a). Dann (2011) emphasises that the transition to secondary school although similar in form and emotion to typically developing peers is qualitatively different and substantially more intense for students with ASD. Specific to the social aspect of transitioning to secondary school, positive peer relationships are found to be protective, and poorer social relations associated with more problems (Hebron, 2017a, 2017b). Odom et al. (2014) refer to the “The developmental period of
adolescence, autism as a spectrum disorder, and the social and organizational ecology of high schools merge to create a “perfect storm” of complexity” (p.124).

Key identified areas for concern during the secondary school years for students with ASD include poorer academic outcomes (Fleury et al., 2014), higher levels of exclusion (Barnard, 2002), problem behaviour (Anderson et al., 2011; Macintosh & Dissanayake, 2006), mental health challenges (Hebron & Humphrey, 2014b) and problems related to social inclusion (Humphrey & Hebron, 2015; Humphrey & Symes, 2010a). The current chapter provides a focus on the social and behavioural aspects of secondary school for students with ASD.

Alongside the challenges of secondary school, adolescence is recognised as a time of change for young people with ASD in terms of the core deficits of ASD and associated behavioural and emotional aspects (McGovern & Sigman, 2005; Seltzer et al., 2004; Woodman et al., 2014). The defining core social difficulties continue to be a major challenge during the adolescent years (Carter et al., 2014). Externalising behaviours are reported to decrease with indicators that internalising behaviours especially depression and anxiety may be more common in adolescents with ASD (Anderson et al., 2011; Shattuck et al., 2007). There is an increase in diagnosed co-morbid mental health conditions with anxiety and depression being the most common (Bellini, 2006).

Factors outside of the student relating to school staff, environment and the other students without ASD are also examined in the literature. Indications are that teachers may have limited knowledge and poor attitudes in relation to inclusion and autism (Gregor & Campbell, 2001; Humphrey & Symes, 2013). Odom et al. (2014) also suggest that in many schools this is related to single subject approach and more independent nature of teaching. Osborne and Reed (2011) demonstrated that student’s
positive secondary school experience was linked to teachers with greater self-efficacy in their competency with students with ASD. McGillicuddy and O'Donnell (2014) demonstrate that most experienced teachers in their qualitative study had the highest knowledge of specialised intervention such as Applied Behavioural Analysis (ABA) or teaching social skills.

Within the Irish context, very little is known about the experience of school for those with ASD. The majority of research appears to have been conducted in the UK (Hebron, 2017b). The cultural nuances and differences in education systems indicate that this experience may differ from country to country. In Ireland students with ASD are predominantly educated in the mainstream, with 152 secondary schools also having special classes (Daly et al., 2016). Parent perceptions reported in Chapter 8 demonstrate the challenges and anxiety related to selecting a school, or ensuring a school has the resources to meet specific needs.

The current chapter reports on a survey of parents and school personnel in relation to the secondary school experience for students with ASD and their reported positive social and problem behaviours in the school setting. A cross-sectional survey design was employed. The research was designed to describe the secondary school experiences for students with ASD in relation to a number of within student factors such as functional cognition, social skills and conversational ability and within school factors such as support structures. It aimed to describe how well the students had settled and felt established in secondary school. It aimed to describe student’s positive social and problem behaviour from the perspective of school personnel and report on these school personnel’s experience in teaching students with ASD. The study also aimed to look at any causative relationships between student and school factors and the students’ behavioural profiles.
9.1.1 Research questions

The research questions were as follows:

In a representative sample of Irish secondary school students with ASD:

- What are students’ levels of conversational ability, functional cognition and functional social skills?
- How do students participate in secondary school in terms of supports, participation and feelings they have settled?
- What size are school settings in terms of numbers of students, teachers and supports?
- What is the level of teacher’s experience with ASD and ABA?
- What are students’ positive social and problem behaviour profiles?
- Are there associations between student and school participation factors?
- Are the within student factors of intellectual disability, conversational ability, functional social skills, functional cognitive skills or level of ASD predictive of problem and positive social behaviour?
- Are the within school factors of level of support and being settled predictive of problem and positive social behaviour?

9.2 Method

9.2.1 Participants

The inclusion criteria were to be a secondary school student with a diagnosis of Autism Spectrum Disorder (ASD) who attended mainstream secondary school in Ireland. One
hundred and three parents directly accessed the online version of the study and three requested paper formats. Recruitment commenced in April 2015 and the study was available online to parents / caregivers for a 12-month period. School personnel connected to the participants were invited to complete questionnaires also. Fifty-nine teachers responded, ten of these teachers chose only to complete the questionnaire relating to the student and not the questionnaire relating to themselves and their school.

### 9.2.2 Measures

Two measures were employed with the parents acting as informants: A descriptive questionnaire, which included variables relating to their child, their schooling and their school experience, and the Social Communication Questionnaire (SCQ; Rutter et al., 2003). Two measures were employed with teachers acting as informants: a descriptive questionnaire relating to the school setting and their experience of ASD and ABA (Lecavalier et al., 2006), and the Nisonger Child Behaviour Rating Form – Teacher Version (NCBRF; Aman, Tassé, Rojahn, & Hammer, 1996).

#### 9.2.2.1 Parent Questionnaires

**9.2.2.1.1 Descriptive Questionnaire**

A non-standard questionnaire (see appendix B) was designed for the purpose of this study with questions relating to student variables i.e., age, rural / urban, gender, age at diagnosis, co-occurring diagnosis, conversational ability, functional social skills, and functional cognitive abilities. It also included questions relating to schooling and school variables, including supports and the student’s school experience.
The measures for conversational ability (one category), functional cognition (four categories) and functional social skills (three categories) were taken from the National Longitudinal Transition Study-2 (NLTS2). This was a prospective study conducted for the U.S. Department of Education between 2001 and 2009. The study included a sample of approximately 11,000 adolescents who were receiving some form of special education (Valdes et al., 2013). These questions were used in previous research looking at social participation levels and autism (Shattuck, Ormond, Wagner, & Cooper, 2011). Cronbach’s alpha for the three-category functional social skill scale was .67 and for the four category functional cognitive skills scale was .66.

School support variables were type of classroom attended, resource allocation, school supports, having and IEP, having school transport, having a behaviour support plan and attend a service for ASD outside school.

School participation and experience variables were whether student had missed school for more than two weeks, whether student had attended different secondary school placements, extracurricular activities in school, extracurricular activities outside school and variables from the NLTS2 study which were feeling settled in school, getting along with students, getting along with teachers, school is challenging, enjoying school, having an adult who cares, school meeting need and receiving necessary supports.

9.2.2.1.2 The Social and Communication Questionnaire

The Social and Communication Questionnaire (SCQ; Rutter et al., 2003) is a 40-item questionnaire derived from the ADR-R algorithm (Lord et al., 1994). It is used extensively in research and as a screening tool for ASD. The SCQ Lifetime version was
used in this study to determine the severity of autism in the student sample. The SCQ comprises of 40 yes/no questions relating to social interaction, communication, abnormal language and stereotyped behaviour. A score of 15 or above indicates the presence of abnormal behaviour that warrants further investigation for the presence of an ASD. Norris and Lecavalier (2010) found the SCQ to have the most supporting research of all level 2 autism screening instruments. It is advised to reduce the cut off score to 11 from 15 for optimal sensitivity and specificity for identifying ASD in research (Stratis & Lecavalier, 2013). The Cronbach’s alpha for the SCQ in this study was .80.

**9.2.2.2 Teacher Questionnaires**

**9.2.2.2.1 Descriptive Questionnaire**

The Familiarity with Applied Behavioural Analysis (ABA) and Familiarity with Autism Spectrum Disorders (ASD) teacher scales are two non-standardised measures developed by Hammer and Lecavalier, 2003. They contain six items each and measure familiarity, exposure and experience with ABA and ASD, rated on a five-point Likert scale (Lecavalier et al., 2006). Cronbach’s alpha for the ABA scale was .93, and for the ASD scale .86. Permission was sought and received to use the Familiarity with ABA and ASD scale from the authors (Lecavalier et al., 2006).

**9.2.2.2 Nisonger Child Behaviour Rating Form**

The Nisonger Child Behaviour Rating Form (NCBRF) was developed as a modified version of the CBRF (Edelbrock, 1985) for children with developmental disabilities (Aman et al., 1996). The revision included the rewording of items to make them more
specific and the addition of 16 items. The measure also has ten positive social items which measure social competence.

The ten positive social items are scored on Likert scales yielding two subscales: Compliant/ Calm and Adaptive/Social. Sixty-two problem behaviour items are also scored on Likert scales yielding six subscales: Conduct Problems, Insecure / Anxious, Hyperactive, Self-injury / Stereotypic, Self-isolated / Ritualistic, and Overly Sensitive. The NCBRF has acceptable internal consistency and adequate concurrent validity against matched subscales on the Aberrant Behaviour Checklist (Aman et al., 2008).

There are limited measures which look at problem behaviours for individuals with ASD (Matson & Nebel-Schwalm, 2007). Many are specifically designed for typical population or those with intellectual disability. These may be inappropriate for population with ASD. This measure was used because the normative data are on children with developmental disabilities and there are reported data from a study specific to children with PDD (Lecavalier, 2006)

Table 9.1 NCBRF subscale, items and range

<table>
<thead>
<tr>
<th>NCBRF Subscale</th>
<th>Items in Subscale</th>
<th>Range of Subscale Answers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive Social</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compliant/Calm</td>
<td>1, 3, 6, 9, 10</td>
<td>0 – 15</td>
</tr>
<tr>
<td>Adaptive Social</td>
<td>2, 4, 5, 7, 8</td>
<td>0 – 15</td>
</tr>
<tr>
<td><strong>Problem Behaviour</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct Problem</td>
<td>2, 4, 7, 8, 10, 12, 26, 36, 40, 48, 54, 57, 63</td>
<td>0 – 39</td>
</tr>
<tr>
<td>Insecure/Anxious</td>
<td>15, 16, 20, 21, 23, 31, 34, 41, 44, 45, 52, 55, 60, 65, 66</td>
<td>0 – 45</td>
</tr>
<tr>
<td>Hyperactive</td>
<td>9, 19, 24, 33, 35, 38, 39, 46</td>
<td>0 – 24</td>
</tr>
<tr>
<td>Self-Injury/Stereotypic</td>
<td>6, 11, 22, 28, 32, 43, 53, 58, 59</td>
<td>0 – 27</td>
</tr>
<tr>
<td>Self-Isolated/Ritualistic</td>
<td>1, 18, 25, 29, 37, 42, 47, 49, 61, 62, 64</td>
<td>0 – 33</td>
</tr>
<tr>
<td>Irritable</td>
<td>5, 14, 17, 27, 51, 56</td>
<td>0 – 18</td>
</tr>
</tbody>
</table>
The teacher version of the scale was used. Cronbach’s alpha was .92. The NCBRF teacher version consists of two sections which are grouped into eight subscales: Positive Social and Problem Behaviour. Positive Social consists of 10 questions on a scale of 0 (Not True) to 3 (Completely or Always True). Problem Behaviour consists of 66 questions on a scale of 0 (Not a Problem) to 3 (Severe Problem), however four of the 66 questions (3, 13, 30, and 50) do not contribute to the scores of the subscales. Higher scores on Positive Social indicate evidence of positive social behaviour; higher scores on Problem Behaviour indicate observations of problem behaviour.

The NCBRF is available for download and research use at https://psychmed.osu.edu/index.php/instrument-resources/ncbrf/.

9.2.3 Procedure

The School of Psychology Ethics Committee, Trinity College Dublin, approved the study. Parent / caregivers participants were invited to participate through multiple methods, with an emphasis on disseminating information about the study through autism support and advocacy groups, parent networks and mainstream secondary schools. Clinical settings were not contacted as they may have elucidated a higher number of students with challenging behaviour. Invitations to participate were disseminated in paper and electronic formats including flyers, letters, emails and social media posts. All invitations detailed the purpose and procedure of the study and directed parents of participants to contact the researcher via email or phone or to go directly to a website and Facebook page where they could find out more details and access the study questionnaire directly (www.teenswithasdinireland.com or https://www.facebook.com/TeensWithAsdInIreland).
Consent and assent forms were also available on this website. Parents could also consent to participate and then complete the form through the website. Alternatively, participants could contact the researcher directly for more information about the study, and email version or paper version of the questionnaire. As part of the questionnaire, parent / caregivers were asked to give a contact name and address for a teacher in their son/ daughter’s school who they believed was best placed to complete a questionnaire in relation to their son / daughter, alternatively they could choose to take delivery of the teacher questionnaires, consent and information and deliver it to the school themselves.

The online questionnaires were produced through Google forms, which could be accessed from the website link or via a link sent over e-mail. Paper versions when requested were created as PDFs from the Google forms and answers were transcribed into the database (Google Sheets). Google docs is a secure cloud-based technology service accessed via email address and password.

Teachers therefore received paper copies of consent, information and questionnaires either via the post or handed to them in an envelope which included a stamped address envelope for return of forms and questionnaires.

Appendix B includes copies of all questionnaires, measures, consent, assent and participant information.

### 9.2.4 Data analysis

All data were stored in a password protected file and managed using Microsoft Excel and SPSS (version 24). The dataset represented 105 participants with ASD for which questionnaires were completed by parents / care-givers and teachers. Much of the missing data come from the teacher questionnaires. 56.7% of participant teachers completed the NCBRF and descriptive questionnaire, 46.4% completed the NCBRF.
Some parent / caregivers omitted responses to certain questions. All answers were included in analysis with counts given in all descriptive statistics for the number in the sample who responded to that specific question. Little’s Missing Completely at Random (MCAR) test was carried out across parent/ caregiver data and teacher data, indicating that the data were missing completely at random (i.e., no identifiable pattern exists in the missing data); $\chi^2 (740) = 488.87, p = 1.0$.

Descriptive statistics were used to report findings in relation to demographics, student and school participation factors. Descriptive statistics were also used to report information about schools and teachers experience and the students’ problem and positive social behaviour profiles. In the Parent Questionnaire, ordinal scales change with each question, so descriptive statistics are presented as a count and percentage for each answer choice available. Correlations were conducted to examine associations between student and school factors. Regression analyses were used to evaluate the predictive value of five within student and two school factors to problem and positive social behaviours. Seven was considered the maximum number of predictor variables which could be used for regression analysis based on recommendations for a minimum of ten events per variable (Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996).

Further analyses were conducted including t-test and ANOVA to examine additional research questions based on the primary research findings. Specifically, in relation to problem and positive social behaviour subscale scores and their relationship with types of schooling, functional cognitive and social skills, anxiety and getting along with peers were examined.
9.3 Results

9.3.1 Demographics

Data were collected for a total of 105 secondary school students with a diagnosis of ASD. In 100% (n = 105) of cases the parents / caregiver informant was the mother. The mean sample age was 15.18 years (SD = 1.60) ranging from 12 to 18 years. The mean age at diagnosis was 8.34 (SD = 3.71) ranging from two to 15 years. 82.9% (n = 87) were male and 17.1% (n = 18) were female. 64.8% (n = 68) lived in an urban setting and 35.2% (n = 37) lived in a rural setting. The mean score on the SCQ as completed by the parent / caregiver was 24.22 with a standard deviation of 7.17. 41.0% (n = 43) attended a service for children with ASD. 20% (n = 21) received support in secondary school from the service.

Table 9.2 Gender, age and geographic area of participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender - male</td>
<td>105</td>
<td>87 (82.9)</td>
</tr>
<tr>
<td>Gender – female</td>
<td>105</td>
<td>18 (17.1)</td>
</tr>
<tr>
<td>Age, years</td>
<td>103</td>
<td>15.18 (1.60)</td>
</tr>
<tr>
<td>Age at Diagnosis, years</td>
<td>100</td>
<td>8.34 (3.71)</td>
</tr>
<tr>
<td>Geographic Area</td>
<td>105</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td></td>
<td>68 (64.8)</td>
</tr>
<tr>
<td>Rural</td>
<td></td>
<td>37 (35.2)</td>
</tr>
</tbody>
</table>

9.3.2 Co-occurring diagnosis

Co-occurring diagnoses were reported by the parent / caregiver. 45.7% (n = 48) had an anxiety disorder, 28.6 % (n = 30) had Attention Deficit Hyperactivity Disorder
(ADHD), 24.8% (n = 26) had developmental coordination disorder (DCD), 21% (n = 22) had an intellectual disability, 15.2% (n = 16) had a sleep disorder, 9.5% (n = 10) had a gastro-intestinal disorder, 2.9% (n = 3) had a seizure disorder and 31.4% (n = 33) had other disorders.

Table 9.3 Co-occurring diagnosis as reported by caregiver

<table>
<thead>
<tr>
<th>Co-occurring diagnosis (n=105)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizure</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>22 (21.0)</td>
</tr>
<tr>
<td>Gastro-intestinal</td>
<td>10 (9.5)</td>
</tr>
<tr>
<td>Sleep Disorder</td>
<td>16 (15.2)</td>
</tr>
<tr>
<td>Developmental Coordination Disorder</td>
<td>26 (24.8)</td>
</tr>
<tr>
<td>Anxiety Disorder</td>
<td>48 (45.7)</td>
</tr>
<tr>
<td>Attention Deficit Hyperactivity Disorder</td>
<td>30 (28.6)</td>
</tr>
<tr>
<td>Other</td>
<td>33 (31.4)</td>
</tr>
</tbody>
</table>

9.3.3 Levels of functioning

Levels of conversational ability, functional social skills and functional cognition were gathered using the NLTS2 measures as previously described.

9.3.3.1 Conversational Ability

2.9% (n = 3) of the participants were reported to have no conversational ability, 15.2% (n = 16) had a lot of trouble carrying out a conversation, 48.6% (n = 51) had some trouble and 32.4% (n = 34) were reported to have no trouble carrying out a conversation.
9.3.3.2 Functional Social Skills

There were three categories of functional social skills. Table 9.3 indicates the frequency and percentages for answers given.

<table>
<thead>
<tr>
<th>Functional Social Skill</th>
<th>N</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How often would your child join group activities without being told?</strong></td>
<td>103</td>
<td></td>
</tr>
<tr>
<td>Very often</td>
<td>7</td>
<td>(6.7)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>55</td>
<td>(52.4)</td>
</tr>
<tr>
<td>Never</td>
<td>41</td>
<td>(39.0)</td>
</tr>
<tr>
<td>Don't know</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td><strong>Would your child make friends easily?</strong></td>
<td>103</td>
<td></td>
</tr>
<tr>
<td>Very often</td>
<td>4</td>
<td>(3.8)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>54</td>
<td>(51.4)</td>
</tr>
<tr>
<td>Never</td>
<td>44</td>
<td>(41.9)</td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
<td>(1.0)</td>
</tr>
<tr>
<td><strong>How often would your child seem confident in social situations?</strong></td>
<td>103</td>
<td></td>
</tr>
<tr>
<td>Very often</td>
<td>3</td>
<td>(2.9)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>61</td>
<td>(58.1)</td>
</tr>
<tr>
<td>Never</td>
<td>39</td>
<td>(37.1)</td>
</tr>
<tr>
<td>Don't know</td>
<td>0</td>
<td>(0)</td>
</tr>
</tbody>
</table>

These three variables were also summed to create a new variable named Social Summary. Social Summary had a range of 0 – 9, with 9 indicating a maximum score i.e., demonstrating the three functional social skills very often. In Social Summary, there were two missing observations, meaning at least one of the values making up Social Summary was missing and the summary score could not be calculated. Of the remaining 103 observations, the median (IQR) was 5.00 (4.00 – 6.00) and the observed
range was 3 to 8. The figure below shows the distribution of scores, along with counts and percentages.

![Distribution of Social Summary variable](image)

Figure 9.1 *Distribution of Social Summary variable*

### 9.3.3.3 Functional Cognition

There were four categories of Functional Cognition. Table 5 indicates the count and percentages for answers given.
Table 9.5 *Functional Cognition*

<table>
<thead>
<tr>
<th>Functional Cognition Questions</th>
<th>N</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can your child dress himself completely?</td>
<td>104</td>
<td></td>
</tr>
<tr>
<td>Very well</td>
<td>51</td>
<td>(48.6)</td>
</tr>
<tr>
<td>Pretty well</td>
<td>44</td>
<td>(41.9)</td>
</tr>
<tr>
<td>Not very well</td>
<td>9</td>
<td>(8.6)</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td>Don't know</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td>Can your child tell time on a clock?</td>
<td>104</td>
<td></td>
</tr>
<tr>
<td>Very well</td>
<td>42</td>
<td>(40.0)</td>
</tr>
<tr>
<td>Pretty well</td>
<td>23</td>
<td>(21.9)</td>
</tr>
<tr>
<td>Not very well</td>
<td>14</td>
<td>(13.3)</td>
</tr>
<tr>
<td>Not at all</td>
<td>24</td>
<td>(22.9)</td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
<td>(1.0)</td>
</tr>
<tr>
<td>How well can your child read and understand common signs?</td>
<td>104</td>
<td></td>
</tr>
<tr>
<td>Very well</td>
<td>65</td>
<td>(61.9)</td>
</tr>
<tr>
<td>Pretty well</td>
<td>26</td>
<td>(24.8)</td>
</tr>
<tr>
<td>Not very well</td>
<td>8</td>
<td>(7.6)</td>
</tr>
<tr>
<td>Not at all</td>
<td>4</td>
<td>(3.8)</td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
<td>(1.0)</td>
</tr>
<tr>
<td>How well can your child get to places outside the home?</td>
<td>104</td>
<td></td>
</tr>
<tr>
<td>Very well</td>
<td>29</td>
<td>(27.6)</td>
</tr>
<tr>
<td>Pretty well</td>
<td>29</td>
<td>(27.6)</td>
</tr>
<tr>
<td>Not very well</td>
<td>17</td>
<td>(16.2)</td>
</tr>
<tr>
<td>Not at all</td>
<td>24</td>
<td>(22.9)</td>
</tr>
<tr>
<td>Don't know</td>
<td>5</td>
<td>(4.8)</td>
</tr>
</tbody>
</table>

These four variables were also summed to create a new variable named Cognitive Summary. Cognitive Summary had a range of 0 – 16, with 16 indicating a maximum score i.e., demonstrating the four functional cognitive skills very often. In Cognitive Summary, there was only one missing observation, meaning at least one of the values making up Cognitive Summary was missing and the summary score could not be calculated. Of the remaining 104 observations, the median (IQR) was 13.00 (10.00 –
14.75) and the observed range was 5 to 16. The figure below shows the distribution of scores, along with counts and percentages.

Figure 9.2 Distribution of Cognitive Summary variable

9.3.4 Schooling

In relation to schooling 55.2% (n = 58) of the students were in full-time mainstream secondary school, 6.7% (n = 7) attended mainstream secondary on a part time basis, 12.4% (n = 13) divided their time between a special class and mainstream classes within a mainstream secondary school, 14.3% (n = 15) attended a special class within a mainstream secondary school on a full time basis and the remaining 10.5% (n = 11) described the students schooling in the other category. All the students in the study were
enrolled in a mainstream secondary school. Some 61.9% (n = 65) were reported to access special classroom for resource or similar teaching purposes. A total of 9.5% (n = 10) were reported to receive one to one resource teaching, 8.6% reported receiving interventions in school for non-academic reasons, and 19% (n = 20) reported other types of resource arrangements.

Some 25.7% (n = 27) had a full time Special Needs Assistant (SNA), 41.9% (n = 44) had no SNA, 29.5% (n = 31) accessed an SNA part-time and 1.9% (n = 2) reported other SNA arrangements. A total of 36.2% (n = 38) had an Individualised Education Plan (IEP) in place, 61.9% (n = 65) did not. 35.2% (n = 37) had school transport provided, 57.1% (n = 60) did not have provided transport and 6.7 (n = 7) reported other transport arrangements. 28.6% (n = 30) reported having a behavioural support plan in place, 71.4% (n = 75) did not have one.

With regard to school placement and attendance 16.2% (n = 17) reported that they had moved / changed secondary school and 28.6% (n = 30) were reported to have missed a period of longer than two weeks of secondary school.

9.3.4.1 School Participation

Some 41.0% (n = 43) reported participation in extra-curricular activities at school, 25.7% (n = 27) reported participating in extra-curricular activities outside of the school setting.

In relation to how well students got along with teachers, it was reported that 25.7% (n = 27) got along very well with them, 54.3% (n = 57) pretty well, 16.2% (n = 17) not very well and 2.9% (n = 3) not at all well. In relation to other students it was
reported that 6.7% (n = 7) got on very well with other students, 61.9% (n = 65) got on pretty well, 25.7% (n = 27) not very well and 4.8% (n = 5) not at all well.

Overall 61.9% (n = 65) of parents reported their son / daughter had found it somewhat or very challenging to settle, 37.1 % (n = 39) reported they had settled somewhat or very easily. A series of five additional questions addressed how the student had settled and experienced secondary school. Table 9.6 displays the numbers and percentages for these five questions. Some 87.5% (n = 92) agreed or strongly agreed that school was challenging for their son / daughter, whilst 10.5% (n = 11) disagreed or strongly disagreed. Some 55.2% (n = 58) agreed or strongly agreed that their son / daughter enjoyed school, with 41.0% (n = 43) disagreeing or strongly disagreeing. 78.1% (n = 32) agreed or strongly agreed that there was an adult in the school who cared about their son / daughter, 16.2% (n = 17) disagreed or strongly disagreed with this statement. Some 61.9% (n = 65) agreed or strongly agreed that the school was good at meeting their son / daughters’ individual needs, 32.4% (n = 35) disagreed or strongly disagreed with this. Some 61.9% (n = 65) agreed or strongly agreed that their son / daughter was getting the support services that they needed to do well at school whilst 33.4% (n = 35) disagreeing or strongly disagreeing with this.
Table 9.6 School Experience of child reported by parents as respondents

<table>
<thead>
<tr>
<th>N=104</th>
<th>Strongly agree n(%)</th>
<th>Agree n(%)</th>
<th>Disagree n(%)</th>
<th>Strongly disagree n(%)</th>
<th>Don’t know n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>School is challenging.</td>
<td>37 (35.2)</td>
<td>55 (52.4)</td>
<td>9 (8.6)</td>
<td>2 (1.9)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>He/she enjoys school.</td>
<td>17 (16.2)</td>
<td>41 (39.0)</td>
<td>28 (26.7)</td>
<td>16 (14.3)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>There is an adult who knows and cares about him/her at school.</td>
<td>42 (40.0)</td>
<td>40 (38.1)</td>
<td>13 (12.4)</td>
<td>4 (3.8)</td>
<td>5 (4.8)</td>
</tr>
<tr>
<td>The school is good at meeting his/her individual needs.</td>
<td>26 (24.8)</td>
<td>39 (37.1)</td>
<td>29 (27.6)</td>
<td>5 (4.8)</td>
<td>5 (4.8)</td>
</tr>
<tr>
<td>He/she is getting the support services from the school that he/she needs to do well in school</td>
<td>28 (26.7)</td>
<td>37 (35.2)</td>
<td>30 (28.6)</td>
<td>5 (4.8)</td>
<td>4 (3.8)</td>
</tr>
</tbody>
</table>

9.3.5 School Information

Forty-eight teachers completed the survey in relation to their school. Table 9.7 indicates means for the numbers of pupils in total in schools, for the numbers who had special
educational needs, for the numbers with ASD, for the numbers of teachers and for the numbers of support staff. These figures indicate that approximately one in every 19 students in these schools has ASD.

Table 9.7 *School Information provided by teachers as respondents*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of students attending their school</td>
<td>48</td>
<td>649.50 (219.52)</td>
</tr>
<tr>
<td>Number of students with special educational needs</td>
<td>48</td>
<td>89.06 (142.96)</td>
</tr>
<tr>
<td>Number of students with autism spectrum disorder</td>
<td>48</td>
<td>33.38 (142.48)</td>
</tr>
<tr>
<td>Number of teachers in their school</td>
<td>48</td>
<td>52.65 (18.36)</td>
</tr>
<tr>
<td>Number of support staff in their school</td>
<td>48</td>
<td>28.77 (143.18)</td>
</tr>
</tbody>
</table>

Teachers (n=48) also gave information about their teaching experience and reported their years of experience with students with ASD with a mean of 5.43 years and SD of 4.48 years. In the Teacher Questionnaire relating to familiarity with ASD and ABA ordinal results are consistent throughout with options ranging on a scale of 1 (Strongly Disagree) to 5 (Strongly Agree) and are therefore presented numerically with the median and interquartile range (IQR). Table 9.8 indicates these responses.
Table 9.8 Teacher information on the familiarity with ASD and ABA scale

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Median (IQR) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledgeable about ASD</td>
<td>48</td>
<td>4.0 (4.0-5.0)</td>
</tr>
<tr>
<td>Taken a course about ASD</td>
<td>48</td>
<td>4.0 (4.0-5.0)</td>
</tr>
<tr>
<td>Attended a training day/workshop on ASD</td>
<td>48</td>
<td>4.0 (4.0-5.0)</td>
</tr>
<tr>
<td>Read a substantial amount about ASD</td>
<td>48</td>
<td>4.0 (4.0-5.0)</td>
</tr>
<tr>
<td>Research the internet regarding ASD</td>
<td>48</td>
<td>4.0 (4.0-5.0)</td>
</tr>
<tr>
<td>Worked extensively with individuals with ASD</td>
<td>48</td>
<td>4.0 (3.0-4.0)</td>
</tr>
<tr>
<td>Familiar with applied behaviour analysis and behaviour modification procedures</td>
<td>48</td>
<td>4.0 (2.0-4.0)</td>
</tr>
<tr>
<td>Frequently use behavioural teaching strategies</td>
<td>48</td>
<td>4.0 (3.0-4.0)</td>
</tr>
<tr>
<td>Taken a course in applied behaviour analysis or behaviour modification</td>
<td>48</td>
<td>2.0 (2.0-4.0)</td>
</tr>
<tr>
<td>Attended a training day/workshop on applied behaviour analysis or behaviour modification</td>
<td>48</td>
<td>2.0 (2.0-4.0)</td>
</tr>
<tr>
<td>Read a substantial amount about applied behaviour analysis or behaviour modification</td>
<td>48</td>
<td>3.0 (2.0-4.0)</td>
</tr>
<tr>
<td>Am a professional who specialises in applied behaviour analysis or behaviour modification</td>
<td>48</td>
<td>2.0 (1.0-3.0)</td>
</tr>
</tbody>
</table>

*scale - 1 (Strongly Disagree) to 5 (Strongly Agree)

9.3.6 Positive Social and Problem Behaviour

Fifty-nine teachers completed the NCBRF in relation to participants. Ordinal results are consistent throughout and are therefore presented numerically with the median and interquartile range (IQR) in Table 9.9.
Table 9.9 Teacher responses on the Nisonger Child Behaviour Rating Form (NCBRF)

<table>
<thead>
<tr>
<th>NCBRF n=59</th>
<th>median (IQR)</th>
<th>Range of subscale answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Social: Compliant/Calm</td>
<td>8.0 (6.0-11.0)</td>
<td>0-15</td>
</tr>
<tr>
<td>Positive Social: Adaptive Social</td>
<td>8.0 (5.0-10.0)</td>
<td>0-15</td>
</tr>
<tr>
<td>Problem Behaviour: Conduct Problem</td>
<td>1.0 (0.0-4.0)</td>
<td>0-39</td>
</tr>
<tr>
<td>Problem Behaviour: Insecure/Anxious</td>
<td>10.0 (5.0-14.0)</td>
<td>0-45</td>
</tr>
<tr>
<td>Problem Behaviour: Hyperactive</td>
<td>6.0 (3.0-10.0)</td>
<td>0-24</td>
</tr>
<tr>
<td>Problem Behaviour: Self-Injury/Stereotypic</td>
<td>1.0 (0.0-3.0)</td>
<td>0-27</td>
</tr>
<tr>
<td>Problem Behaviour: Self-Isolated/Ritualistic</td>
<td>8.0 (4.0-12.0)</td>
<td>0-33</td>
</tr>
<tr>
<td>Problem Behaviour: Irritable</td>
<td>4.0 (1.0-7.0)</td>
<td>0-18</td>
</tr>
</tbody>
</table>

9.3.7 Correlations

Due to the evaluated variables being largely ordinal, the non-parametric Spearman’s rho statistic was used to evaluate the relationships between possible predictive variables on the parents’ questionnaire.

9.3.7.1 Student variables - age and diagnosis

There was a negative correlation between age at diagnosis (M = 8.34 SD = 3.71) missing more than two weeks of school, r = -.34, getting to places (functional cognition), r = -.36, and SCQ score, r = -.43, p = ≤ .001. There was a positive correlation between age at diagnosis (M = 8.34 SD = 3.71) and enjoying school r = .40, p = ≤ .001.

There was a negative correlation between students age (M=15.18 SD=1.60) and having had different school placements, r = -.30, p = ≤ .001.

In terms of co-occurring diagnosis there was a positive correlation between having an intellectual disability and telling the time on a clock (functional cognition), r = .42, and reading common signs (functional cognition), r = .34, p = ≤ .001. There was a
negative correlation between having an intellectual disability and enjoying school, $r = -0.27$ and attending an outside service $r = -0.33$, $p = \leq 0.001$.

### 9.3.7.2 Functional skills

The students' levels of conversational ability was positively correlated with joining in group activities (functional social skills), $r = 0.27$, making friends easily (functional social skills), $r = 0.33$; reading common signs (functional cognitive skills), $r = 0.29$; getting to places (functional cognitive skills), $r = 0.37$, and SCQ score $r = 0.5$, $p = \leq 0.001$.

There were positive correlations between how often the student was likely to join-in group activities (functional social skills) and making friends easily (functional social skills), $r = 0.41$; levels of social confidence (functional social skills), $r = 0.36$, joining in extra-curricular activities, $r = 0.27$, enjoying school $r = 0.31$, and SCQ score $r = 0.31$, $p = \leq 0.001$.

There were positive correlations between making friends easily (functional social skills) and levels of social confidence (functional social skills), $r = 0.48$; dressing him/herself (functional cognition), $r = 0.26$; getting along with other students, $r = 0.27$, and SCQ score $r = 0.31$, $p = \leq 0.001$.

There were positive correlations between levels of social confidence (functional social skills) and getting to places (functional cognition), $r = 0.32$, joining in extra-curricular activities, $r = 0.30$, getting along with other students, $r = 0.26$, and SCQ score $r = 0.27$, $p = \leq 0.001$.

The students’ ability to dress themselves (functional cognition) was positively correlated with the other functional cognitive variables; telling the time, $r = 0.26$, reading common signs $r = 0.40$ and getting to places outside the home $r = 0.33$, $p = \leq 0.001$. It was
also positively correlated with receiving school transport, \( r = .27 \) and SCQ score, \( r = .30 \), \( p = \leq .001 \).

### 9.3.7.3 Schooling and school support

There were positive correlations between attending a special ASD class and receiving resource, \( r = .29 \), receiving school transport, \( r = .30 \), having attended different school placements, \( r = .25 \), participating in extracurricular activities outside of school, \( r = .28 \), attending an outside service, \( r = .26 \) and SCQ score, \( r = .35 \), \( p = \leq .001 \).

Having an SNA was positively correlated with having missed more than two weeks of school, \( r = .28 \), and having a behaviour support plan, \( r = .24 \), \( p = \leq .001 \).

Having and IEP was positively correlated with receiving school transport, \( r = .27 \) and the school meeting the students’ needs, \( r = .26 \), \( p = \leq .001 \).

Receiving school transport was positively correlated with being settled in school, \( r = .28 \), getting along with teachers, \( r = .30 \), and attending an outside service, \( r = .31 \), \( p = \leq .001 \).

### 9.3.7.4 School participation and experience

For those who had missed more than two weeks of secondary school, it was positively correlated with having attended different school placements, \( r = .35 \), and finding school challenging, \( r = .46 \). It was negatively correlated with feeling settled, \( r = -.54 \), getting along with students, \( r = -.35 \), getting along with teachers, \( r = -.32 \), and enjoying school, \( r = -.56 \), \( p = \leq .001 \).

Settling into secondary school was positively correlated with getting along with other students, \( r = .42 \), getting along with teachers, \( r = .58 \), enjoying school, \( r = .58 \),
school meeting needs, $r = .28$, and receiving necessary supports, $r = .30$. It was negatively correlated with finding school challenging, $r = -.56$, $p \leq .001$.

There was a positive correlation between getting along with other students and getting along with teachers, $r = .46$, and enjoying school, $r = .32$, $p \leq .001$.

Getting along with teachers was negatively correlated with finding school challenging, $r = -.42$. It was positively correlated with enjoying school, $r = .50$, having and adult who cares, $r = .32$, school meeting needs, $r = .47$, and having necessary supports, $r = .46$, $p \leq .001$.

Enjoying school was positively correlated with having and adult who cares, $r = .38$, school meeting needs, $r = .32$, and having necessary supports, $r = .30$, $p \leq .001$.

Having an adult who cares was positively correlated with the school meeting need, $r = .61$ and having the necessary supports $r = .60$, $p \leq .001$.

There was a positive correlation between school meeting need and having the necessary support $r = .83$, $p \leq .001$.

### 9.3.8 Regression analysis

Each of the seven NCBRF subscales was regressed against seven variables in order to determine if they were predictive of the behaviours. The variables were intellectual disability, conversational ability, socially confident (functional social skill), get to places (functional cognitive skill), SCQ score, schooling (level of support), and how well the student settled.

For six of the subscales the model was not significant.

1. Compliant/calm: The model is not significant ($p=0.339$) and the input variables are not strong predictors of a NCBRF Compliant/Calm score with 13.8% of the
variation in the score being determined by the values of the seven explanatory variables.

II. Conduct problems: The model is not significant (p=0.879) and the input variables are not strong predictors of a NCBRF Conduct Problem score with 5.6% of the variation in the score being determined by the values of the seven explanatory variables.

III. Insecure/Anxious: The model is not significant (p=0.701) and the input variables are not strong predictors of a NCBRF Insecure/Anxious score with 8.4% of the variation in the score being determined by the values of the seven explanatory variables.

IV. Hyperactive: The model is not significant (p=0.803) and the input variables are not strong predictors of a NCBRF Hyperactive score with 6.9% of the variation in the score being determined by the values of the seven explanatory variables.

V. Self-Injury/Stereotypic: The model is not significant (p=0.107) and the input variables are not strong predictors of a NCBRF Self-Injury/Stereotypic score with 19.9% of the variation in the score being determined by the values of the seven explanatory variables.

VI. Self-Isolated/Ritualistic: The model is not significant (p=0.584) and the input variables are not strong predictors of a NCBRF Self-Isolated/Ritualistic score with 10.0% of the variation in the score being determined by the values of the seven explanatory variables.

VII. Irritable: The model is not significant (p=0.745) and the input variables are not strong predictors of a NCBRF Irritable score with 7.7% of the variation in the score being determined by the values of the seven explanatory variables.
For Adaptive Social the model was significant (p=0.043) and the variables of social confidence (functional social skills) and schooling (level of support) were the most influential. Some 23.8% of the variation is determined by the seven input variables.

### 9.3.9 Further analysis

In light of the mainly non-significant regressions some further analysis was carried out to look into any possible relationships between the NCBRF subscales and student and school variables.

#### 9.3.9.1 T-test for all subscales: mainstream schooling vs special class

For these tests, the schooling variable was recoded into a new variable called Binary School which has two values: 1) Mainstream schooling, full or part time, and 2) Special class, any. The fifth option of other was recoded as missing within the new variable Binary School as it cannot be determined what this means.

With this new coding, in the total of 105 observations, 12 had missing values. Of the 93 observations with valid answers, 65 (69.9%) are classified as Mainstream, and 28 (30.1%) are classified as Special Class. Fifty-four of the observations had both scores for the NCBRF scales and the schooling question in the parent questionnaire. Of these, 32 were mainstream and 22 were in a special class. Table 9.10 reports on the t-tests.
Table 9.10 *Differences in types of schooling and NCBRF subscales*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mainstream n=32</th>
<th>Special Class n=22</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compliant/Calm</td>
<td>8.19 (3.17)</td>
<td>9.14 (3.30)</td>
<td>ns(^t)</td>
</tr>
<tr>
<td>Adaptive Social</td>
<td>7.19 (2.60)</td>
<td>8.55 (3.85)</td>
<td>ns(^w)</td>
</tr>
<tr>
<td>Conduct Problem</td>
<td>3.59 (5.04)</td>
<td>1.95 (2.54)</td>
<td>ns(^w)</td>
</tr>
<tr>
<td>Insecure/Anxious</td>
<td>11.88 (7.25)</td>
<td>8.86 (8.42)</td>
<td>ns(^t)</td>
</tr>
<tr>
<td>Hyperactive</td>
<td>7.38 (5.30)</td>
<td>6.45 (4.27)</td>
<td>ns(^t)</td>
</tr>
<tr>
<td>Self-Injury/Stereotypic</td>
<td>1.66 (2.73)</td>
<td>2.45 (2.99)</td>
<td>ns(^t)</td>
</tr>
<tr>
<td>Self-isolated/Ritualistic</td>
<td>8.50 (5.75)</td>
<td>7.00 (4.55)</td>
<td>ns(^t)</td>
</tr>
<tr>
<td>Irritable</td>
<td>4.69 (4.15)</td>
<td>4.05 (3.50)</td>
<td>ns(^t)</td>
</tr>
</tbody>
</table>

Values in mean (SD); ns = not significant; \(^t\) independent t-test; \(^w\) Welch's t-test

There was no significant difference in any of the subscale scores between the types of schooling.

### 9.3.9.2 Correlation of social summary scores with each subscale

Due to the non-normal distribution of the Social Summary score, the nonparametric Spearman’s rho was used to measure correlation. None of the subscales were significantly correlated with the composite Social Summary score.

### 9.3.9.3 Correlation of cognitive summary scores with each subscale

The nonparametric Spearman’s rho was used for the cognitive summary score as well. One of the subscales was found to be significantly correlated: Self-Injury/Stereotypic. For this subscale, a moderate negative correlation was found to exist (rho = -0.466, p < 0.001). This suggests that with higher scores on the self-injury/stereotypic scale, the functional cognitive summary score is lower.
9.3.9.4 ANOVA with child’s schooling on anxiety subscale

A one-way ANOVA with Tukey’s post-hoc test was run to compare the anxiety subscale scores among the five answers for types of schooling. The ANOVA showed a significant difference between at least two of the five groups (p=0.023) and Tukey’s post-hoc test revealed that the significant difference lies between the ‘full-time special class or unit in secondary school’ and ‘other’ groups (p=0.022).

Figure 9.3 Plot of mean score of Insecure/Anxious subscale by schooling

9.3.9.5 ANOVA for all subscales: with child gets along with others in school

One-way ANOVAs with Tukey’s post-hoc test were run for each subscale to compare the subscale scores among the four answers for how a child gets along with others in
their school. Only one of the subscales (Insecure/Anxious) showed a significant
difference between at least two of the four groups (p=0.007) and Tukey’s post-hoc test
revealed that a significant difference lies between the ‘very well’ and ‘not very well’
groups (p=0.042) as well as the ‘very well’ and ‘not at all well’ groups (p=0.038).

Figure 9.4 Plot of mean score of Insecure/Anxious subscale by getting along with other
students

None of the other seven subscales shows any significant differences between the four
answer choices.
9.3.9.6 Power analyses

Post-hoc power analyses were run to determine the strength of the tests with the observed differences and given sample sizes. T-tests showed between 45-55% power. ANOVAs showed between 27-32% power. Regressions showed 90% power. Low powers in the t-tests and ANOVAs are due to the sample size, since the sample was split.

9.4 Discussion

This study aimed to report on the secondary school factors, experience and participation for a sample of 105 students with ASD who attended mainstream secondary school in Ireland. There was a focus on problem and positive social behaviours and any relationships between these and student and school factors.

9.4.1 Students

With regard to students with ASD, one of the acknowledged challenges for secondary school systems is the diversity and heterogeneity of the students themselves (Kucharczyk et al., 2015). However, the core deficits of social communication and interaction remain consistent over time and individuals (McGovern & Sigman, 2005). The findings in relation to functional social skills and conversational skills embody this. The sample for this study represents secondary student with ASD across levels of support and ability. The wide range of SCQ scores demonstrates this (M=24.22 SD 7.17). A large majority reported functional social skills difficulties with between one third and half the sample being reported to never feel comfortable in social situation (37%), never make friends easily (41%) and never joining in group activities without
being told (43%). No student was reported as engaging in these combined types of social activities very often. In terms of conversational skills, 67% of the sample were reported to have some trouble to no ability carrying out a conversation.

In contrast to this the students reported functional cognitive skills represented a much greater spread, with 11 students being reported has having the maximum level of functional cognitive skills, and the large majority reporting getting on well or very well in these areas.

These results demonstrate the range of ability and difference within the sample, but also the clear identified challenge of social skill and communication for all students with ASD. The relationships inferred by the correlations would also indicate that social and conversational ability may influence how well students get along with others, how much they enjoy school and how they participate in extra-curricular activities. Functional cognition appears to relate more to the presence or not of an intellectual ability and the level of support required or severity of the students with ASD. Educational responses to cognitive and academic skill can be implemented, but meeting the social need is a far greater challenge for secondary school systems (Dillon & Underwood, 2012; Dillon et al., 2016). There is also a key concern, that social difficulties are having an impact not only on how the student with ASD gets on with others in school, but also in terms of important skill acquisition such as independence (Hume, Boyd, Hamm, & Kucharczyk, 2014).

The spread of co-morbid conditions represents what is widely reported in the literature, and supports this sample as being representative of secondary students with ASD (Gillberg and & Billstedt, 2000; Simonoff et al., 2008)

Of particular note is the large number (45.7%) who were reported to have anxiety disorders by their parent. This high incidence of anxiety is also widely
represented in the literature (Anderson et al., 2011; Shattuck et al., 2007; White et al., 2009). With some evidence that adolescence with ASD are internalising behaviours more than externalising, and that internalising anxiety may also lead to acting out or outbursts (Hebron & Humphrey, 2014b). Trigger and causes for this high rate of anxiety are purported to include stressors in the school environment and problems with social communication skills and peer relationships (Farrugia & Hudson, 2006). Teacher reporting of anxiety in this study was also quite high, but the NCBRF median scores for anxiety may not reflect this as strongly as the parent reports. Although only two students (3.4%) had no score on the insecure/anxious subscale, with all others receiving more than one observation of insecure/anxious behaviours, with a large range of scores between one and 39. Twenty one percent of students were reported to have an intellectual disability (ID). This is on the lower side of the estimated rates of ID and ASD (between 26% to 68%) (Weiss & Burnham Riosa, 2015). It may be accounted for by the fact these were all students attending mainstream secondary school. Students with ASD and ID are differentiated in much of the research relating to adolescents. It is reported that those with ID will display more challenging behaviour and have more ASD symptoms compared to non-ID peers with ASD diagnosis who will lessen in terms of symptoms and challenging behaviours (McGovern & Sigman, 2005; Shattuck et al., 2007). Results show a relationship between ID and functional cognitive skills. There was also a relationship between having an ID and enjoying school less. The ID group were not looked at separately in relation to school experience or behaviours. But there was an indication that those with lower functional cognition scores demonstrated more stereotypical / self-injurious behaviour. This would align with studies finding that students with ID were more likely to display challenging behaviours (Shattuck et al., 2007).
9.4.2 Schooling

Sixteen percent of students were reported to have moved secondary school, 28.8% had missed school for more than two weeks. Indicators from the correlations are that those who had missed school may have found it more difficult to settle and are more likely to have moved secondary school. It is reasonable to assume that a portion of these students had moved or missed school as they were not settled. Humphrey (2008) reports findings in the UK that indicate 21% of students with ASD are excluded from school at least once (Barnard, Prior & Potter, 2000). It is clear that students with ASD and their parents have a harder time finding suitable secondary school placements and many struggle to settle (Falkmer et al., 2012; Humphrey, 2008; Whitaker, 2007).

In terms of participation and the school experience the majority of parents (87.5%) reported that school was challenging for their son / daughter. Parental concern and lack of satisfaction with school appears to grow as their child with ASD gets older. There is a parental perception that secondary school teachers’ lack of knowledge and understanding of ASD can contribute to a more challenging school experience (Falkmer et al., 2015).

9.4.3 Teachers

The teachers in this study reported to be quite familiar with ASD and the majority reported having been on a course or taken time to learn about ASD. They were less familiar with applied behaviour analysis and although they reported using behavioural strategies, the majority had no training or professional development in the area. Segall and Campbell (2012) demonstrated that teachers’ level of knowledge is a strong
predictor of awareness of best practice in inclusion and teaching. However, knowledge does not necessarily lead to use of empirically supported practice or evidence-based intervention methods (Fennell & Dillenburger, 2018; Humphrey & Symes, 2013; Segall & Campbell, 2012). The current study demonstrated that to a certain extent, there was a high reported level of knowledge, but less familiarity with empirically supported best practice for those with ASD.

### 9.4.4 Positive Social and Problem Behaviour

A central aim of this study was to describe the presentation of problem and social behaviours in the sample. Problem behaviour is a concern for teachers and schools in terms of management and understanding. Lecavalier et al. (2006) demonstrated a link between stress in teachers and problem behaviour presentation of students with ASD. Most notably conduct and disruptive or rule breaking behaviours were most stressful. Research is limited in this age group and unknown in an Irish context. Indicators are that problem behaviour may lessen in this age group with the exception of those with ID (Levy & Perry, 2011; Matson, Mahan, Hess, Fodstad, & Neal, 2010).

Comparisons to NCBRF norms should be viewed with caution for a number of reasons. Firstly, the sample that norms are calculated from is a clinical sample of children with varying developmental, physical and intellectual delays including autism. The authors also present these norms as means and standard deviations (Tassé, Aman, Hammer, & Rojahn, 1996). Median and IQR are presented in the results of this study because these ranked scores of the NCBRF are not a continuous measure and tend to be skewed, so mean/SD doesn't give a coherent description of the data. The age range presented closest to this study’s sample is 10 to 16 years, whereas the range in this study was 12 to 18 years. However, table 9.12 presents comparison of this study’s mean and
SD scores with the norms presented by Tassé et al. (1996) for the teacher version age 10 to 16 years as a point of information. It also presents findings from Lecavalier (2006) for n=105 non-clinically referred young people with a Pervasive Developmental Disorder diagnosis between the ages of 13 and 21 years.

Table 9.11 Comparison of study data to previous published data

<table>
<thead>
<tr>
<th>NCBRF subscale</th>
<th>Tassé et al. (1996) Mean (SD)</th>
<th>Lecavalier (2006) Mean (SD)</th>
<th>Current study Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Social: Compliant/Calm</td>
<td>5.96(3.78)</td>
<td>7.9(3.3)</td>
<td>8.56(3.23)</td>
</tr>
<tr>
<td>Positive Social: Adaptive Social</td>
<td>5.36(3.44)</td>
<td>6.6(3.0)</td>
<td>7.74(3.14)</td>
</tr>
<tr>
<td>Problem Behaviour: Conduct Problem</td>
<td>13.20(11.00)</td>
<td>7.2(7.4)</td>
<td>3.29(4.97)</td>
</tr>
<tr>
<td>Problem Behaviour: Insecure/Anxious</td>
<td>10.70(10.40)</td>
<td>9.0(7.8)</td>
<td>11.20(8.27)</td>
</tr>
<tr>
<td>Problem Behaviour: Hyperactive</td>
<td>11.10(6.60)</td>
<td>8.7(5.5)</td>
<td>7.17(4.87)</td>
</tr>
<tr>
<td>Problem Behaviour: Self-Injury/Stereotypic</td>
<td>5.10(5.73)</td>
<td>4.7(5.5)</td>
<td>2.2(3.18)</td>
</tr>
<tr>
<td>Problem Behaviour: Self-Isolated/Ritualistic</td>
<td>9.06(6.95)</td>
<td>8.8(5.0)</td>
<td>7.9(5.54)</td>
</tr>
<tr>
<td>Problem Behaviour: Irritable</td>
<td>7.25(5.37)</td>
<td>6.4(4.9)</td>
<td>4.64(4.34)</td>
</tr>
</tbody>
</table>

In comparison to the measures norms (Tassé et al., 1996) the results from this study appear lower in all problem behaviours other than insecure/anxious and higher in positive social behaviours. In comparison to the Lecavalier (2006) study, the findings are very similar, although again insecure/anxious is higher in this study. It is interesting to note that insecure/anxious is the only higher score and reflects the understanding that adolescents with ASD shift in their problem behaviours towards more internalising behaviours (Hebron & Humphrey, 2014b).

Lecavalier (2006) also presents prevalence data for each behavioural item in the NCBRF for a sample of 437 children between the ages of three and 21. Percentages are presented for problem behaviour items which were reported by teachers as occurring
often/being a moderate problem and occurring a lot / being a severe problem. Table 9.12 represents the most reported problematic behaviours and the least problematic behaviours as reported in his study and the current study.

Table 9.12 *Comparison of prevalence data from Lecavalier (2006) with current study*

<table>
<thead>
<tr>
<th>NCBRF item (subscale)</th>
<th>Lecavalier (2006)</th>
<th>NCBRF item (subscale)</th>
<th>Current Study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Most frequently reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*Easily distracted (hyperactive)</td>
<td>59.5</td>
<td>*Difficulty concentrating (hyperactive)</td>
<td>50.8</td>
</tr>
<tr>
<td>*Easily frustrated (irritable)</td>
<td>53.6</td>
<td>Withdrawn, uninvolved with others (self-isolated/ritualistic)</td>
<td>45.8</td>
</tr>
<tr>
<td>*Difficulty concentrating (hyperactive)</td>
<td>50.1</td>
<td>*Easily distracted (hyperactive)</td>
<td>45.7</td>
</tr>
<tr>
<td>*Short attention span (hyperactive)</td>
<td>47.4</td>
<td>*Easily frustrated (irritable)</td>
<td>40.7</td>
</tr>
<tr>
<td>Stubborn (no subscale)</td>
<td>44.4</td>
<td>*Short attention span (hyperactive)</td>
<td>37.3</td>
</tr>
<tr>
<td><strong>Least frequently reported</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*Bites self (self-injury / stereotypic)</td>
<td>4.8</td>
<td>Cruelty or meanness to others (conduct problem)</td>
<td>1.7</td>
</tr>
<tr>
<td>Lying cheating (no subscale)</td>
<td>4.6</td>
<td>Gets in physical fights (conduct problem)</td>
<td>1.7</td>
</tr>
<tr>
<td>Feels worthless (insecure/anxious)</td>
<td>4.1</td>
<td>Gouges self, puts things in ears nose etc. (self-injury / stereotypic)</td>
<td>1.7</td>
</tr>
<tr>
<td>*Steals (conduct problem)</td>
<td>3.1</td>
<td>Runs away from adults (conduct problem)</td>
<td>1.7</td>
</tr>
<tr>
<td>Threatens to harm self (self-injury / stereotypic)</td>
<td>1.3</td>
<td>*Bites self (self-injury / stereotypic)</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physically harms or hurts self on purpose (self-injury / stereotypic)</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>*Steals (conduct problem)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowingly destroys property (conduct problem)</td>
<td>0</td>
</tr>
</tbody>
</table>

*Matched item

The top-rated items show similarity across both studies, particularly for items representing hyperactivity. The bottom rated items have less commonality, but mainly represent conduct problems and stereotypical / self-injury subscales for both studies.

Within the current study, the subscales of conduct problem and stereotypical / self-injury were the least reported. While the other four problem behaviours, i.e.,
insecure/anxious, hyperactive, self-isolated/ritualistic and irritable was more frequently reported at approximately the same levels for the sample (see Table 9.13). Referring back to the study on teacher stress, it is encouraging to observe that the most stressful behaviours from a teacher perspective are the least reported in the current study (Lecavalier et al., 2006). The relatively frequent reporting of behaviours linked to hyperactivity may reflect a number of issues for the current study group, potentially including sensory processing differences, co-occurring ADHD, and adjustment to the more concentration focused demands of the secondary school environment. This finding warrants further examination as difficulties with attention and concentration and being easily distracted can be a significant impairment to school participation and academic attainment (Ashburner et al., 2010). Research finds that approximately 50% of those with an ASD diagnosis may also fulfil the criteria of an ADHD diagnosis (Sinzig, Walter, & Doepfner, 2009). Almost 30 percent of students in this study were reported to have a co-morbid diagnosis of ADHD. Studies have also revealed that although symptoms of ADHD lessen with age in those with ASD, this is more specific to the hyperactive symptoms while inattention may persist into adolescence and adulthood (Sinzig et al., 2009). This has important functional implications for students with ASD participation in secondary school and is substantiated by findings from this study.

In terms of within student and school factors which may influence positive social and problem behaviours, seven variables were selected as the most likely predictors. However, these variables did not represent strong predictors in six of the models i.e., on one positive social behaviour and the five problem behaviours. The adaptive social regression model did show significant relationship with social confidence and mainstream schooling (i.e., those not accessing special classes).
Reasons for these non-significant findings are most likely related to the small sample size and the low reported incidence of problem behaviours. Although limited, other research has demonstrated similar lack of relationships between behaviours and child and school factors. Gender has been shown not to have an effect in several studies (Aman et al., 1996), and as such was not included as a variable in the regressions. The seven chosen variables represented were intellectual disability, conversational ability, socially confident (functional social skill), get to places (functional cognitive skill), SCQ score, schooling (level of support), and how well the student settled. Regression models were limited to seven variables based on sample size, number of observations and ensuring power. However, it was concluded that these seven variables reflected the aims of the study and a spread of possible predictive variables.

Having an intellectual disability has been demonstrated to be related to more problem behaviours in adolescence than any other within student factor (McCarthy, 2007). Adaptive skills (similar to functional skills) show limited relationships in Lecavalier’s (2006) study also, with some evidence that lower adaptive skills are associated with less pro-social behaviour and less anxiety. Students attending full-time special classes in this study had the lowest rating for anxiety, which may bear some similarity to this finding.

Levels of ASD as measured by the SCQ appeared to correlate with many of the within student factors, but do not relate to behavioural presentations. Previous research has also found this lack of association (Chandler et al., 2015; Simonoff et al., 2008). Reasons for this are unknown, but there is a view that the ASD diagnosis may ‘trump’ other risk factors. In other words, the diagnosis in some way attenuates behavioural expectations.
There is some evidence that inclusive educational contexts can promote positive behaviours (Osborne & Reed, 2011; Woodman et al., 2015). But conversely support within special schools and special classes has been shown to improve student functioning (Reed et al., 2011). The regression models showed no influence for schooling i.e., level of classroom support in all problem behaviours subscales. However, being in fulltime classroom did appear to have a positive relationship with adaptive social skills. No conclusion can be drawn as to whether this relationship is causal.

Osborne and Reed (2011) study demonstrated the mixed relationships between school factors and student with ASD functioning. Whilst small groupings within secondary schools with other students with SEN had a positive influence on functioning, it had a negative impact on social problems. Social behaviour was also impeded by high number of support staff but improved behavioural and emotional problems. This complex relationship between the benefits and challenges of the type of classroom environment and supports and the individual student is also highlighted when looking specifically at the anxious / insecure subscale; those with lowest anxiety were in special classroom on a full-time basis. So, it would seem that special classroom arrangements and supports can positively influence problem behaviours, being in a mainstream environment is more positive for social skills.

The student’s behavioural presentation did not appear to be related to how well they had settled in school. 61.9% of parents reported the student had found it challenging to settle in secondary school. There is some evidence that it takes students with ASD longer to settle into secondary school, and the students themselves report finding mainstream secondary school stressful (Bellini, 2006; Humphrey & Lewis, 2008a; Saggers, 2015). However, the challenge of settling in does not appear to influence the students’ behavioural presentation.
### 9.4.4.1 Anxiety

Anxiety was reported by a large number of parents and teachers and is also reported in the literature as impacting on many secondary students with ASD (Bellini, 2006; Farrugia & Hudson, 2006; White et al., 2009). The NCBRF subscale score of anxiety/insecure was investigated in relation to types of schooling. There was a significant difference between those in full-time special class or unit and those whose schooling was described in the other category. This ‘other group’ were not further investigated by the questionnaire. This group would require further analysis to draw any conclusions but may well represent those who were having the least satisfactory secondary school experience and were failing to access mainstream school in a regular fashion. Anxiety may be an expression of a difficult school-child fit. Woodman et al’s (2015) study of contextual factors point to levels of inclusion in academic and social activities may be a predictor of better outcomes for students with ASD, even after accounting for levels of functioning and intellectual disability.

The anxiety/insecure group also showed the only relationship with the ‘getting along with others’ variable. Higher anxiety/insecure scores represented those who got on least well with others. Although these results should be interpreted with caution. The relationship between displaying higher anxiety and weaker social relationships is one which has been represented by other researchers (Ambler et al., 2015; Bellini, 2006).

### 9.5 Conclusions and Limitations

This survey was unique in its combination of addressing within student, school and factors relating to problem and positive social behaviour in a sample of secondary
students with ASD. Although these factors have been addressed separately through previous research, no known study has examined them in combination. The findings reveal some interesting associations between students’ presentations in the secondary school years and their emotional / behavioural presentation. Of note is the predictive relationship between social confidence, mainstream schooling and higher adaptive social skills. Although unsurprising, it supports the theory of inclusive education and contact with mainstream peers as being useful to developing social skill and relationships (Osborne & Reed, 2011). Higher anxiety also appeared to be predictive of weaker social relationships, leading to questions as to the nature of the anxiety and if lack of social experiences may feed this pattern. This may suggest that guided peer experiences could assist in the alleviation of this anxiety.

The descriptive findings in relation to students’ experience of secondary school, particularly in reference to limited reported participation in social activities and extracurricular activities mirror findings in the international research, and the concern that students with ASD are not getting the same social participation opportunities as their mainstream peers (Falkmer et al., 2012; Obrusnikova & Cavalier, 2011; Orsmond, Krauss, & Seltzer, 2004; Shattuck et al., 2011).

The highlighted shift towards more internalising problem behaviours such as anxiety and away from externalising behaviours was also reflected in this study (Hebron & Humphrey, 2014b). The teacher reported levels of anxiety were high compared to other studies and may reflect the challenging environment of Irish secondary schools.

9.5.1 Limitations

The study sample size was small and may have under represented certain aspects of the school experience. This was a particular challenge as the NCBRF was reliant on teacher
informants, many of whom did not return questionnaires. As parents were the gate
keeper to teachers, follow up with those who did not respond was difficult. Some of the
statistical tests were underpowered for this reason. Although it should be noted that
despite widespread and varied attempts to recruit more participants to the study, there
were challenges to recruitment. It would appear that parents and teachers of students
with ASD are potentially an over-researched group in Ireland. Anecdotal reports
conveyed scepticism as to the value of research unless it could be translated into
concrete outcomes for students and families.

The diagnosis of ASD was reported by parents and was not verified in this
convenience sample. The self-selection of parents for the study may have biased it
towards those who had a more challenging time in secondary school.

This study did not include the voice of the students with ASD themselves and
therefore cannot make any conclusions about their subjective experience. Many of the
previously published qualitative studies have made use of the student voice (Saggers,
2015; Saggers et al., 2012).

In conclusion this study has highlighted many of the experiential, behavioural
and social aspects to attending secondary school for students with ASD in Ireland.
Findings indicate that the core social deficit of ASD remains a major barrier to students’
experience, with high levels of anxiety and distractibility being the primary teacher
reported problem behaviours. Those with opportunities and confidence to socialise
appeared to have less anxiety and better adaptive social skills. A key recommendation
from this study is to address opportunities to provide more social experiences for
students with ASD in secondary schools in a structured and non-anxiety promoting
manner.
10 Chapter Ten: A Study of Peers Knowledge and Understanding of ASD

10.1 Introduction

Compared to primary school, the secondary school context introduces much greater amounts of time with peers and more complex social networks. Students’ attitudes towards each other and their interest in making social connections brings social relationships to prominence in secondary schools. The social environment creates opportunities and vulnerabilities for all students. These social opportunities rely on interpersonal skills and interest between peers in forming social connections (Tonnsen & Hahn, 2016). Whilst many students with ASD may have to learn how to instigate and formulate social skills and connections, there is still an element which is outside of their control. Social inclusion and connections are at the behest of peers. If other students perceive those with ASD as being different, have negative attitudes towards this or are potentially fearful of making peer relations with a student with a disability, it creates a social barrier. It is known that students who have more positive attitudes about peers with ASD are more likely to behave in a pro-social manner towards them (Tonnsen & Hahn, 2016). Although very few studies have examined how peers understand, conceptualise and develop their attitudes towards those with ASD, especially in secondary schools. Many students have not had the opportunity to develop knowledge and understanding or formulate attitudes about students with ASD.

Parents from the study in chapter 8 make this point in relation to their child with ASD in secondary school. The parents in this study articulated the challenge for the students in making social connections. Many believed their child deeply wanted to have
more social situations and connections in secondary school, but they were not enabled by the social environment in school, and a noted absence of support for social skills and social opportunities (Cremin et al., 2017).

Within the Irish educational context, some secondary school students with ASD will also have a separate classroom or unit within the secondary school. This may bring a participatory barrier to educational and social opportunities within the mainstream environment. Their mainstream peers become very aware of their differences by their placement alone. When general education participation becomes more restricted for students as does their opportunities to socialise with their mainstream peers (Carter et al., 2008; Hughes et al., 2011).

Chapter 9’s findings are also indicative of the struggle to make social connections for students with ASD in Irish secondary schools. With 37% of the sample never feeling confident in social situations, 41% reporting never making friends easily and 43% never joining in group activities without being told. As well as interventions which aid students with ASD to become more confident in social situations, the peers who they are hoping to socialise with need to be better understood. It appears that for many peers their conceptions of ASD and those with ASD are flawed (Campbell et al., 2011). Their lack of understanding of their peers with ASD may cause social barriers. Recent research by Bottema-Beutel and Li (2015) sheds light on this. They report that often adolescents with ASD are excluded not only based on stereotyped attributions of difference, but also the genuine difficulty of social interaction. Adolescents are less likely to choose ‘low-status’ group members for social activities. The research highlights the complex moral and social judgements adolescents make about including others socially, but emphasises that an understanding of ASD, and the social difficulties
it encompasses can bring a different response to inclusion from peers. In particular for activities within school which are open to everyone, students do not view it as acceptable to leave a person with ASD out once they understand the social disability or disadvantage the student with ASD may have (Bottema-Beutel & Li, 2015).

10.1.1 Knowledge

Campbell and Barger (2011) discuss Piaget’s stages of cognitive development in the context of developing knowledge about ASD in adolescence. The formal operations stage commences from about 11 years on, this is when children develop physiologically based concepts of illness. They will often explain and understand illness and disability based on malfunctioning body parts or systems. Moving into adolescence and adulthood they will learn to conceptualise psychophysiological accounts of illness. This means they can understand that behaviour and illness processes may interact. For example, they make the connection between stress and depressive illness. In terms of knowledge about autism, the limited research reflects that middle school students (12 to 14 years) have fairly good knowledge of autism from a physiological perspective. Although a small percentage of students in Campbell and Barger’s study believed that autism was communicable and was not attributed to any type of brain dysfunction. Those with prior experience of autism had better knowledge. It is surmised that for many, as autism is not a physical or obvious disability, they may not have encountered it. Knowledge may have been formulated from media and hearsay. It is understandable then that without accurate knowledge students may inadvertently attribute behaviour in a negative fashion, for example lack of eye contact as being rude (Campbell & Barger, 2011). However, information or knowledge alone is not enough to change behaviour or attitude
towards peers with disability. Shifts in attitude and intentions also need to happen (Swaim & Morgan, 2001).

10.1.2 Attitude and Intentional Behaviour

Attitude and intentional behaviour are related concepts. Authors who have addressed these concepts with regard to peers of students with disabilities cite Gottlieb and Gottlieb assertions from their seminal study into students’ attitudes in 1977. They used a framework which separated attitude into two separate dimensions cognitive and conative (Campbell, 2008). Cognitive attitudes refer to statements or beliefs about the person with a disability, whilst conative attitudes are statements of intent to behave or interact with the person, these have become known as behavioural intentions.

Further analysis of behavioural intention demonstrated that these are often also contextually and disability specific. For example, students may express positive behavioural intentions towards a wheelchair user for academic based activity, but less positivity for recreational activity. Campbell et al. (2004) reported overall lower behavioural intentions of elementary / primary school aged children towards a peer with ASD. However, the context of the activity did appear to influence these intentions e.g., academic or social.

For secondary school aged students, the separation of cognitive attitude and conative/ behavioural intention has been demonstrated in the limited research with these students particularly showing variance between the two concepts (Campbell, 2008). More recent models of attitude have also demonstrated this theoretically. Campbell (2008) summarises as follows: (1) behavioural intentions are viewed as separate from attitudes, and (2) behavioural intentions are identified as one of the best predictors of
actual behaviour. The second point is particularly vital as it implies that improving intentional behaviour will be predictive of actual behaviour change.

### 10.1.3 Influencing factors

Gender, age and prior experience of autism are presented as the most influential factors in students’ knowledge, attitude and intentional behaviours (Campbell & Barger, 2014).

Previous research with 12 to 14-year olds suggests more favourable attitudes toward children with special needs are often expressed by females and those with previous exposure to disabilities (Campbell, 2007). However reports are very mixed and inconsistencies are also confounded by the age of the participants. In studies of younger children and related to more severe disabilities, girls often display more positive attitudes (Slininger, Sherrill, & Jankowski, 2000). More recent studies of college students addressing openness to students with ASD have shown limited gender effects with boys being more willing to socialise in their free time with their peers with ASD (Nevill & White, 2011). A study of adolescents by Fleva (2014) found no real gender effect for intentional behaviour and attitude towards a hypothetical peer with Asperger Syndrome. Gender is considered a significant factor, but other variables such as age, environment and levels of ASD of target peers influence on outcomes are also impactful.

Age is also discussed as a factor in knowledge, attitude and intentional behaviour, with cognitive development obviously having a large impact on knowledge as previously discussed. As children reach adolescence there appears to be a shift in relation to behavioural intentions, younger children are more likely to be inclusive in relation to recreational activities and their peers. Fleva (2014) acknowledges that this
may not be specifically towards children with ASD or other disabilities, but more likely a representation of the more acute social awareness of adolescents.

Peers with previous experience of autism has been demonstrated by Campbell’s work to have better and more accurate knowledge about autism (Campbell, 2007; Campbell & Barger, 2011; Campbell et al., 2011). It is less clear how this may impact on attitude and behavioural intention.

10.2 Neurodiversity and Autism Acceptance

The conceptualisation of autism has shifted in the past decade with the advent of self-advocacy by individuals with autism and the neurodiversity movement. How well this is understood by secondary school students is unknown. Related to this is a societal shift away from a medical model of cure and cause towards a more nuanced biopsychosocial perspective of amelioration and inclusion (Castro & Pinto, 2013). This recognition of rights and individuality mirrors advocacy movements for many other types of disability, and also reflects the conceptualisation of disability by the World Health Organisation (WHO), international classification of functioning, disability and health (ICF) (2001). Autism awareness has moved to autism acceptance through the neurodiversity movement. The point is that by awareness people are merely learning what is wrong or different about those with autism, by acceptance there is a mind-set shift towards understanding, accommodating and accepting the diversity that comes with having autism. Kapp et al. (2013) addressed this shift by assessing conceptions of autism and neurodiversity amongst people with autism, parents and other adults. Despite differences in their reported understanding of neurodiversity, with people with autism having the highest awareness, the total sample represented an endorsement of
acknowledging difference and deficits whilst also celebrating the autistic identity. This biopsychosocial perspective, which gives identity to those with autism, but also acknowledges the need for interventions may bring a new perspective to understanding how peers conceptualise their peers with ASD. There is very limited research into conceptions of autism and neurodiversity. This is vital if people are to understand autism and demonstrate autism acceptance. Campbell et al’s (2011) study of middle school student’s spontaneous definitions of autism gives some insight into this. They found that just over 70% of students had an accurate conception, but often this lacked any detail or understanding, whilst almost 30% had an inaccurate or no conception of autism. Very few students reported understanding core symptoms and attributed many differences to being ‘abnormal’ or in some way deficient. Students frequently articulated information about identity, causes, and consequences of autism, but did not pay attention to core symptoms especially social challenges, or consider the individual with autism. This ‘them’ and ‘us’ phenomenon was also found in unpublished qualitative study of Irish secondary school students (Compton, Hughes, Kelly, & Cremin, 2015). It is suggested that without a ‘holistic’ conception of autism it will be difficult for students to display acceptance of the peers with ASD (Gillespie-Lynch et al., 2015; Kapp et al., 2013). Autism advocacy movements such as AsIAm (www.AsIAm.ie) an Irish autism advocacy initiative also reflect this belief.

The purpose of this study is to document and describe fourth year secondary school students’ knowledge, attitude, intentional behaviour of autism and their conceptions of neurodiversity. It also aims to investigate factors relating to gender and previous experience of autism as potential predictors of knowledge, attitude, intentional behaviour and concepts related to neurodiversity.
10.3 Method

10.3.1 Participants

This study employed a cross-sectional survey design. Participants were 72 fourth year / transition year students from two co-educational secondary schools in Leinster, Ireland. Both schools also had dedicated autism classrooms.

Transition year (TY) is a programme taken after Junior Cycle and before the two-year Leaving Certificate programme in secondary schools. It is considered a bridge between these two phases of secondary school and has an emphasis on teaching students to take on more responsibility for their own learning experiences and decision making. TY is designed to be a broad educational experience, including work experiences, trips and community service. Students have the opportunity to participate in experiential learning and activities. Assessment is usually on an ongoing basis and can include school-based assessment of projects or portfolios (Ireland, 1993).

All of the students were in TY and between the ages of 15 and 16 years. The schools were co-educational non-fee paying secondary schools. One was in an urban setting in North Dublin, the other on the outskirts of a town in North Leinster, outside Dublin. There were 40 boys and 32 girls in the sample. The study was inclusive of all students attending TY in both schools, this may have included students with ASD, although no student attending the special ASD class in either school was a TY student.

10.3.2 Measures

10.3.2.1 Knowledge of Autism Scale

The Knowledge of Autism scale (KOA) is a 10-item True/False scale designed by Campbell and Barger (2011). Its purpose is to measure secondary students’ knowledge
of the cause, course, symptoms, and communicability of autism. It includes questions about potential misinformation students may have about autism. It is the only published scale which has been designed with applicability to secondary school students (Flesch-Kincaid Grade Level 6-6). It has reported weak internal consistency Cronbach’s of .47, due to the small number of items and dichotomous scoring system. It is recommended by the authors that individual items be reported and may be more meaningful than the overall score. Cronbach’s alpha for this study is .48, and as such the recommendations of Campbell and Barger (2011) are taken into account.

### 10.3.2.2 Shared Activity Questionnaire

The Shared Activity Questionnaire (SAQ) is a 24-item questionnaire. It was originally developed for use with primary school aged students (Morgan, Walker, Bieberich, & Bell, 1996). It was adapted and validated by Campbell (2008) for use with middle school students and their intentional behaviours towards a hypothetical peer with ASD. The scales items are grouped in three domains. These are general social (SAQ- GS) which relates to engaging in social activities within school with a student with autism, academic (SAQ - A) which relates to engaging in academic activities and active recreation (SAQ - AR) which relates to active recreational activities outside of the school setting. The SAQ has been found to have good internal consistency (Cronbach’s a = .93 for the total scale, .82 for general social, .82 for the academic, .84 for active recreational).

For completion participants indicate their willingness to engage in listed behaviours with a hypothetical peer with ASD as follows: Yes (2), Maybe (1), or No (0). The SAQ uses three computer-drawn faces that correspond with each response: a “smile” face (Yes), a “frown” face (No), and a “straight” face (Maybe). To assess behavioural intentions towards the hypothetical peer, participants receive three points
for every "yes" response, two points for every "maybe" response and a one point for every "no" response. Thus, the maximum score a participant can get is 72 (a "Yes" response to all items) and the minimum score is 24 (a "No" response to all items). Higher scores indicate greater behavioural intentions to include the hypothetical peer.

On the suggestion of the authors some small adaptations were made to ensure its compatibility with older students and Irish culture e.g., ball game changed to sports event and zoo changed to cinema. Cronbach’s alpha for the total SAQ score for this study was .93, consistent with the reported internal consistency in the literature.

10.3.2.3 Societal Attitude to Autism Scale

The Societal Attitudes Towards Autism scale (SATA) is an autism specific scale designed to measure attitudes towards autism in the general population. It is differentiated from other measures as it is not specific to children with autism and it is not designed with a specific subgroup of informants in mind. The SATA was the result of pilot work on 75 items, to exploratory and confirmatory factor analyses on a 45-item version with 475 undergraduate university students, with the resulting measure being the 16 item SATA. It demonstrated sound psychometric properties with this sample of university students. The SATA showed strong content and construct validity as evidenced by known groups discrimination, and predicted associations with an attitude towards disability measure, an autism preference item, and a measure of implicit attitudes towards disabilities (Flood, Bulgrin, & Morgan, 2013). High scores indicate more accepting attitude to autism. There are 16 statements which participants indicate on a 4-point scale whether they strongly disagree, disagree, agree or strongly agree with the statement. For this study Cronbach’s alpha was calculated as .74, which indicates
good internal consistency.

### 10.3.2.4 Survey of Neurodiversity Conceptions

Aspects of a survey used to gain better insights into autism and neurodiversity concepts for parents, people with autism and their friends were used (Kapp et al., 2013). This is the only sourced survey of these concepts. It was adapted for the secondary school students by excluding questions relating to demographics, background and having autism and including questions on; definitions and awareness of the term neurodiversity, selection of emotions about how they would feel about having autism, specific questions about their views on parenting a child with autism, which reflect neurodiversity / medical model dichotomy and their view on what causes Autism. Students were also asked if they had prior experience of autism. Reliability and validity of the survey is unknown as it has only been utilised as a survey in one published study.

### 10.3.3 Procedure

The School of Psychology Ethics Committee, Trinity College Dublin, approved the study. Authors of the SAQ were contacted to request permission to use the questionnaire. Other questionnaires were available for use by researchers through publications.

The project was discussed and presented to staff at AsIAm, an autism advocacy organisation in Ireland. They made some suggestions in relation to secondary schools with ASD classrooms who may be receptive to the project and also agreed to endorse the research. Principals of Secondary Schools with autism classrooms in the Leinster region were contacted via e-mail with information about the research. Two schools expressed interest and were invited to participate in the study. The sample is
representative of three classes in total (one in one school and two in the other school). These students were recruited through parent and student information leaflets with informed consent forms (parents) returned prior to data collection. Twenty-four students in first school and 48 in second consented to participate. This represented a 93.5% agreement to participate, i.e., 72 out of 77 invited students.

Data collection took place in a classroom in the school setting and was supervised by a teacher in the school. Students were given information about the study, and signed assent forms prior to completion of the measures. Anonymous coded questionnaires, with detailed information on how to complete each questionnaire were given to each student. They were given as much time as needed within the scheduled class to complete the questions (45 minutes). The questionnaires were then gathered by the teacher and given to researcher. The measures were presented in the following order, KOA, SAQ, SATA and neurodiversity survey. The SAQ gives an account of a hypothetical peer with ASD, it was considered that by putting this second it allowed students a reference point or clarity around how someone with ASD may present for the following measures, but not for the KOA.

10.3.4 Data Analysis

All data were stored in a password protected file and analysed with SPSS (version 24). The dataset represented 72 students’ responses. Analysis showed no problems with out of range or non–random missing data (Little MCAR test). There was very little missing data as students were given very clear instructions and asked to check all their answers. Descriptive statistics were used to report findings in relation to the student factors of gender and prior experience of Autism. Descriptive statistics were also used to present the findings from all the measures.
The KOA scale has ten true / false questions. Overall scores were calculated and reported. Each individual question was also analysed individually for numbers of correct responses.

The SATA scale has 16 statements. Overall scores were calculated and reported. Each individual statement was also descriptively analysed and ranked.

The SAQ has three separate domains (general social, recreation and academic) as well as a total score for scoring and analysis. Each domain was descriptively analysed.

The gender and prior experiences of autism variables were analysed in terms of their association with knowledge, attitude and intentional behaviour and attitudes to parenting questions. For data which were not normally distributed Mann–Whitney U tests were used, for normally distributed data t-test were carried out and for categorical data chi-square analysis were used. It is common for questionnaire responses on scales to have excessive kurtosis and / or skew (Jamieson, 2004). Linear regressions were also carried out to investigate the predicative nature of these variables.

For the questions relating to neurodiversity and autism. Participants were asked to indicate if they had heard of neurodiversity and if so where. Regardless of their response to this they were also asked the question “what do you think neurodiversity is?” answers were coded into mutually exclusive categories of “relating to brain differences”, “relating to groups of people who are different”, “don’t know” and “other”.

Participants were asked a series of six questions relating to parenting and autism, which highlighted a dichotomy between medical model and neurodiversity views but could be answered without prior awareness of either. These questions were
designed by Kapp et al. (2013) to try and establish underlying views about difference and deficit in children with autism.

Participants selected emotions based on how they would feel if they had autism. The frequency of positive and negative endorsed emotions was calculated.

Finally, participants answered a question on what they thought caused autism. Answers were coded into mutually exclusive categories as used by Kapp et al. (2013), but with the inclusion of a ‘don’t know’ category, all answers were also coded into accurate or inaccurate causal categories. The categories were, ‘biological’ i.e., defining autism as genetic in nature or attributing cause to a biological or neurological difference; ‘social – environment’ i.e., others’ behaviour or attitude is causative of autism; “physical – environment” i.e., causes in the non-human context such as vaccines or toxins; “multiple causes” i.e., several overlapping categories or multiple causes; “validity rejection” i.e., autism is just part of natural variation of humans; “don’t know” and “other” where answers were either ambiguous or did not fit in the other given categories. For both open ended questions 20% of the sample was double coded by a second researcher (14 responses).

10.4 Results
The study group were all transition year students between the ages of 15 and 16 years. Gender and experience of autism were identified as predictor variables, table 10.2. The self-report measures demonstrated a variance of responses as shown in Table 10.1.
Table 10.1 *Mean scores on KOA, SATA and SAQ*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (SD)</th>
<th>MIN / MAX*</th>
<th>Potential Range**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of Autism (KOA)</td>
<td>8.57 (1.43)</td>
<td>5.0 – 10.0</td>
<td>1.0 – 10.0</td>
</tr>
<tr>
<td>Societal Attitude to Autism (SATA)</td>
<td>49.17 (6.02)</td>
<td>32.0 – 60.0</td>
<td>16.0 – 64.0</td>
</tr>
<tr>
<td>Shared Activity Questionnaire (SAQ)</td>
<td>55.67 (10.32)</td>
<td>29.0 – 72.0</td>
<td>24.0 – 72.0</td>
</tr>
<tr>
<td>SAQ – general social</td>
<td>19.38 (3.55)</td>
<td>9.0 – 24.0</td>
<td>8.0 – 24.0</td>
</tr>
<tr>
<td>SAQ – academic</td>
<td>19.02 (3.89)</td>
<td>9.0 – 24.0</td>
<td>8.0 – 24.0</td>
</tr>
<tr>
<td>SAQ – active recreation</td>
<td>17.26 (4.32)</td>
<td>8.0 – 24.0</td>
<td>8.0 – 24.0</td>
</tr>
</tbody>
</table>

*this is the observed range of responses from sample (N=72)

**this is the valid range of responses possible on the measure

Table 10.2 *Predictor Variables of the Study Group (n = 72)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>40</td>
<td>55.6</td>
</tr>
<tr>
<td>Female</td>
<td>32</td>
<td>44.4</td>
</tr>
<tr>
<td>Experience of autism</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>36</td>
<td>50.0</td>
</tr>
<tr>
<td>No</td>
<td>36</td>
<td>50.0</td>
</tr>
</tbody>
</table>
Individual breakdown of responses to the KOA and the SATA are given in table 10.3 and 10.4. Responses to the five questions relating to attitude to parenting are reported in table 10.5.

Table 10.3 *KOA percentage of correct responses*

<table>
<thead>
<tr>
<th>Item (n=72)</th>
<th>Percent correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lasts a week</td>
<td>100.0</td>
</tr>
<tr>
<td>Difficult time looking at others</td>
<td>72.2</td>
</tr>
<tr>
<td>Does not affect brain</td>
<td>86.1</td>
</tr>
<tr>
<td>Cannot do normal activities</td>
<td>75.0</td>
</tr>
<tr>
<td>Repeat what is said</td>
<td>86.1</td>
</tr>
<tr>
<td>Rock back and forth</td>
<td>81.9</td>
</tr>
<tr>
<td>Trouble talking or expressing self</td>
<td>90.3</td>
</tr>
<tr>
<td>Can easily move from one activity to next</td>
<td>79.2</td>
</tr>
<tr>
<td>Need extra help to learn</td>
<td>94.4</td>
</tr>
<tr>
<td>You can catch autism</td>
<td>91.7</td>
</tr>
</tbody>
</table>
Table 10.4 *SATA breakdown – descending order by mean*

<table>
<thead>
<tr>
<th>Factor (n=72)</th>
<th>Mean*</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with autism should be fully integrated into mainstream classes.</td>
<td>2.22</td>
<td>0.85</td>
</tr>
<tr>
<td>A person with autism is a financial burden to his/her family.</td>
<td>2.66</td>
<td>0.73</td>
</tr>
<tr>
<td>People with autism cannot understand other people’s feelings.</td>
<td>2.76</td>
<td>0.95</td>
</tr>
<tr>
<td>Individuals with autism are incapable of living on their own.</td>
<td>2.80</td>
<td>0.76</td>
</tr>
<tr>
<td>People with autism should be encouraged to marry someone with autism.</td>
<td>2.87</td>
<td>0.83</td>
</tr>
<tr>
<td>Students with autism who are mainstreamed into regular classrooms are a distraction to students without autism in that classroom.</td>
<td>2.90</td>
<td>0.84</td>
</tr>
<tr>
<td>A person with autism is an emotional burden to his/her family.</td>
<td>3.09</td>
<td>0.85</td>
</tr>
<tr>
<td>People with autism should not have children.</td>
<td>3.09</td>
<td>0.85</td>
</tr>
<tr>
<td>I would be uncomfortable hugging a person with autism.</td>
<td>3.11</td>
<td>0.98</td>
</tr>
<tr>
<td>People with autism should be institutionalised for their safety and others</td>
<td>3.15</td>
<td>0.89</td>
</tr>
<tr>
<td>People with autism are incapable of forming relationships and expressing affection.</td>
<td>3.18</td>
<td>0.93</td>
</tr>
<tr>
<td>I would be comfortable sitting next to a person with autism in the same class.</td>
<td>3.31</td>
<td>0.76</td>
</tr>
<tr>
<td>People with autism should not engage in romantic relationships.</td>
<td>3.34</td>
<td>0.80</td>
</tr>
<tr>
<td>If a facility to treat people with autism opened in my community, I would consider moving away</td>
<td>3.51</td>
<td>0.76</td>
</tr>
<tr>
<td>People with autism should have the opportunity to go to college**</td>
<td>3.79</td>
<td>0.44</td>
</tr>
</tbody>
</table>

*each question is ranked on a scale of 1 (strongly disagree), 2 (disagree), 3 (agree) and 4 (strongly agree) – all items reverse coded except **
Table 10.5 Neurodiversity and parenting questions

<table>
<thead>
<tr>
<th>Item (n=72)</th>
<th>Percent Yes / Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents should seek a cure</td>
<td>61.1</td>
</tr>
<tr>
<td>Parents should teach child to develop skills</td>
<td>98.6</td>
</tr>
<tr>
<td>Parents should teach child to appear more like a typical person</td>
<td>61.1</td>
</tr>
<tr>
<td>Parents should understand autism as part of their child’s identity</td>
<td>93.1</td>
</tr>
<tr>
<td>Parents should try to learn why their child is on the autism spectrum</td>
<td>86.1</td>
</tr>
<tr>
<td>Parents should learn to speak their child’s language</td>
<td>94.4</td>
</tr>
</tbody>
</table>

10.4.1 Gender and Previous Experience of Autism as factors

The Shapiro-Wilk test indicates that the data were not normally distributed for all measures except the SATA. Non-parametric tests were used for all data except SATA. An alpha level of .05 was used for all tests.

Mann-Whitney U tests were performed to test the distribution of the five measures between genders, a t-test was used for the SATA. A significant difference was found in the general social score on the SAQ (U=457, p=0.037) with females scoring higher than males. No other significant differences were found between genders.

Mann-Whitney U tests for five measures and t-tests for the SATA were also performed to evaluate differences in questionnaire scores between those who have had previous experience with autism and those who have not. Students with previous experience of autism scored significantly higher on the KOA than students who had no previous experience (U=364.57, p=0.001). No other significant differences were found between scores.

Chi-square analysis was used to examine the relationship between previous experience of autism, gender and the six attitude to parenting questions. The
relationship between previous experience and seeking a cure was significant, $c^2(1, n=72) = 5.844, p=0.016$. Those with previous experience of autism were less likely to believe parents should seek a cure. No other significant relationships were found.

Table 10.6 *Scores on the KOA, SATA and SAQ by gender*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Gender</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total SATA</td>
<td>Male</td>
<td>40</td>
<td>48.90</td>
<td>6.58</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>32</td>
<td>49.50</td>
<td>5.32</td>
</tr>
<tr>
<td>SAQ general social</td>
<td>Male</td>
<td>40</td>
<td>18.50</td>
<td>3.97</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>32</td>
<td>20.46</td>
<td>2.60</td>
</tr>
<tr>
<td>SAQ academic</td>
<td>Male</td>
<td>40</td>
<td>18.52</td>
<td>4.36</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>32</td>
<td>19.65</td>
<td>3.14</td>
</tr>
<tr>
<td>SAQ active recreation</td>
<td>Male</td>
<td>40</td>
<td>16.47</td>
<td>4.54</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>32</td>
<td>18.25</td>
<td>3.88</td>
</tr>
<tr>
<td>Total SAQ</td>
<td>Male</td>
<td>40</td>
<td>53.50</td>
<td>11.53</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>32</td>
<td>58.37</td>
<td>7.93</td>
</tr>
<tr>
<td>Total KOA</td>
<td>Male</td>
<td>40</td>
<td>8.725</td>
<td>1.35</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>32</td>
<td>8.375</td>
<td>1.51</td>
</tr>
</tbody>
</table>

Table 10.7 *Scores on the KOA, SATA and SAQ by experience of ASD*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Experience of ASD</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total SATA</td>
<td>yes</td>
<td>36</td>
<td>49.63</td>
<td>6.37</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>36</td>
<td>48.69</td>
<td>5.70</td>
</tr>
<tr>
<td>SAQ general social</td>
<td>yes</td>
<td>36</td>
<td>19.47</td>
<td>3.14</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>36</td>
<td>19.27</td>
<td>3.95</td>
</tr>
<tr>
<td>SAQ academic</td>
<td>yes</td>
<td>36</td>
<td>19.44</td>
<td>3.54</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>36</td>
<td>18.61</td>
<td>4.21</td>
</tr>
<tr>
<td>SAQ active recreation</td>
<td>yes</td>
<td>36</td>
<td>17.08</td>
<td>4.21</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>36</td>
<td>17.44</td>
<td>4.48</td>
</tr>
<tr>
<td>Total SAQ</td>
<td>yes</td>
<td>36</td>
<td>56.00</td>
<td>9.51</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>36</td>
<td>55.33</td>
<td>11.19</td>
</tr>
<tr>
<td>Total KOA</td>
<td>yes</td>
<td>36</td>
<td>9.16</td>
<td>0.94</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>36</td>
<td>7.97</td>
<td>1.59</td>
</tr>
</tbody>
</table>
A series of multiple linear regression analyses were conducted to investigate if gender or previous experience of autism were predictive of the knowledge, attitude and behavioural intention outcomes.

For gender and previous experience of autism being predictive of knowledge of autism (KOA), the total variance explained by the model was 18% \( F(2,69) = 7.526 \ p<.01 \). Only previous experience of autism was statistically significant as an individual predictor of KOA (beta = .41, \( p<.01 \)).

For gender and previous experience of autism being predictive of general social behavioural intentions (SAQ-GS), the total variance explained by the model was not quite significant \( F(2,69) = 3.108 \ p=.051 \). Only gender (being female) was statistically significant as an individual predictor of SAQ-GS (beta = -.29, \( p<.05 \)).

For gender and previous experience of autism being predictive of total behavioural intentions (SAQ), the total variance explained by the model was not significant. However, gender (being female) was statistically significant as an individual predictor of SAQ (beta = -.25, \( p<.05 \)).

For all other linear regressions there was no significant results.

10.4.2 Concepts of Neurodiversity and Autism

Some 5.6% (n=4) of the sample were aware of the term neurodiversity, the rest had not heard of the term. Definitions of neurodiversity were given by 44% (n=32) of participants, the rest did not answer or stated they did not know. 30.5% (n=22) defined
it as some type of brain difference, 4% (n=3) gave an explanation to do with groups of people who are different, and 8% (n=6) gave other explanations.

A total of 131 emotions were selected for how you might feel about having autism, with 31 answers indicating they didn’t know how they would feel. A total of 31 positive emotions (happy, proud, content and excited) were indicated, this is 19% of total emotions selected. 93 negative emotions (sad, overwhelmed, frustrated, angry, ashamed and confused) were indicated, this is 57% of total emotions selected. 17 neutral emotions were selected and 31 don’t knows, 30% of total emotions selected. The most commonly selected emotions were frustrated and confused.

Table 10.8 Coded responses for causes of autism on Survey of Neurodiversity Conceptions

<table>
<thead>
<tr>
<th>Causes of Autism</th>
<th>Percent % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological</td>
<td>35 (21)</td>
</tr>
<tr>
<td>Social Environment</td>
<td>1.6 (1)</td>
</tr>
<tr>
<td>Physical environment</td>
<td>3.3 (2)</td>
</tr>
<tr>
<td>Multiple causes</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>18.3 (11)</td>
</tr>
<tr>
<td>Validity rejection</td>
<td>3.3 (2)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>38.3 (23)</td>
</tr>
</tbody>
</table>

Sixty participants answered the question on causes of autism. Of the 37 answers given 13 of them were coded as inaccurate. These included four answers which referred to either having missing or too many chromosomes, corruptions of the brain, mothers taking drugs and getting sick during pregnancy, infants getting sick and contracting autism and exposure to negative developmental experiences.
10.5 Discussion

Levels of knowledge about autism in the current study were assessed using the KOA (Campbell & Barger, 2011). Although this measure has poor internal consistency it is the only measure which has been previously used with secondary school aged students. Harrison, Slane, Hoang, and Campbell (2016) provide a systematic review of literature to examine measures used to assess ASD knowledge, forty-four measures were identified, but only 7% had strong psychometric qualities. The KOA was identified by the authors as being in the strong psychometric category. The 15 and 16-year olds in the current study demonstrated an overall high knowledge of ASD. The largest gaps in knowledge were identified on questions relating to core symptoms of eye contact, transitioning and participating in activities with between 28 and 20% giving inaccurate answers. No student thought that autism only lasted a week, and about 8% though it was communicable. Although a low number, it is concerning that any student thought that they could ‘catch’ autism. About 14% did not know autism was associated with brain based aetiology. Campbell and Barger (2011) observe that inaccuracies in understanding aetiology and believing it is contagious demonstrates reasoning that falls below the expected level for secondary school students, and even though it’s a small minority represents a concern about how these students may perceive their peers with ASD. In comparison to Campbell and Barger (2011) who reported results from a sample who were between 12 and 14 years, the sample in the current study was between 15 and 16 years. The number of correct responses was higher in this study and may reflect this greater cognitive maturity. Sixteen-year olds in a study in Northern Ireland demonstrated similar high levels, which were comparable to an adult level of knowledge (Dillenburger et al., 2017). Indeed, studies of university and college students also demonstrated high levels of knowledge about autism (Gillespie-Lynch et
al., 2015). But all of these studies are caveated with the contention that high levels of
knowledge may not transfer to attitude and inclusive behaviour. Also, even small gaps
in knowledge may impact on an individual’s conceptions about autism, leading to false
beliefs, which may alter behaviour and social intentions (Campbell & Barger, 2011;
Gillespie-Lynch et al., 2015). Students were also asked what they thought caused
autism, despite high levels of knowledge, they were less able to articulate a cause, with
38% indicating they didn’t know the cause and 35% of answers given being coded as
inaccurate. Campbell and Barger (2011) hypothesise that knowledge measures may not
accurately reflect the complexity of understanding needed to fully articulate cause,
which is below the level of reasoning expected at this stage of adolescent development.
Knowledge of autism in this group may be quite shallow, informed by social media or
hearsay, or misinterpreted in some way. As ASD has very few physical indicators,
those without first-hand experience of knowing someone with ASD may have incorrect
conceptions or very shallow knowledge. An unpublished mixed methods study with
Irish secondary school students (Compton et al., 2015) indicated similar high levels of
basic knowledge about autism, but negative perceptions and little intent to socialise
with students with ASD in their school. Studies of knowledge also consistently find
that those with previous experience of ASD, or who know someone with ASD have
higher levels of knowledge (Campbell & Barger, 2011; Dillenburger et al., 2017;
Dillenburger, McKerr, Jordan, Devine, & Keenan, 2015; Gillespie-Lynch et al., 2015;
White et al., 2016). This study was no exception, and those with previous experience
scored higher on the KOA. Though knowledge is an important factor and relevant in
terms of the development of attitude and understanding, it is acknowledged that high
levels of knowledge do not predict attitude and intentional behaviour (Nevill & White,
2011).
Cognitive attitudes were measured using the SATA (Flood et al., 2013) and conative attitudes or behavioural intentions by the SAQ (Morgan et al., 1996). These are both self-report measures. The SAQ has been used widely in studies addressing intentional behaviour towards children with differences and disabilities (Campbell, 2008). SATA has been less widely used but was chosen to reflect a wider cognitive societal attitude from the students, outside of their peer group specifically. Surprisingly few studies have focused on secondary school students’ attitudes and intentional behaviours towards their peers with ASD. Although stigma and attitudes towards gender and race have been readily considered, far less emphasis is given to disability groupings (O’Driscoll, Heary, Hennessy, & McKeague, 2012). This is despite a wealth of research into many aspects of autism within the school system, and plenty of research into improving social skills for those with ASD. It may be that this is to the detriment of understanding peers’ role in social inclusion, as enhancing social connections is focused on the student with ASD skills.

Both measures of attitude advise that higher scores are indicative of more positive attitudes, however no cut off is given which may lead to subjective interpretation. de Boer, Pijl, and Minnaert (2012) provide a useful rule of thumb in their review of attitude scales. Study outcomes were considered as positive when the percentage of positive scores was above 70% or when the mean score was above 3.5 (on a five-point Likert scale). Scores were counted as neutral if the percentage of positive scores was between 30% and 70%. For the SAQ as it was a three-point scale it would indicate a mean above 1.5. For the SATA the four-point Likert scale challenges this interpretation somewhat as there is no central or neutral score i.e., two is disagree and three is agree, therefore scores below a mean of three may be considered negative in terms of attitude. For the SAQ this indicates high behavioural intentions for the
study group. In terms of the SATA, the percentage of positive scores is 62.5% being indicative of the neutral range.

When looking at individual questions, based on this rule of thumb, it is interesting to note that on the SATA, the question with the lowest mean score is “children with autism should be fully integrated into mainstream classes”. This is perhaps the question which the students had most direct experience of and could be indicative of attitudes which may not be inclusive.

Comparison to other studies is again hampered by them either being with younger primary school aged children or older third level student. Studies of younger children mainly report neutral attitudes (de Boer, Pijl, Minnaert, & Post, 2014). Gender, age and experience of ASD are reported to be the main influencing factors on attitude. Older students have more positive attitudes, this is linked to increases in knowledge and understanding. When interpreting group scores for attitude within a school setting, variance is an important consideration. Where even small groups of students hold a negative attitude, this can have a knock-on effect towards the student with ASD (de Boer et al., 2014). In this study it is observed that the range of scores is quite large particularly in the SAQ, with students’ scores representing almost the full range of potential scores, indicating that despite the large numbers with very positive intentions, there remains a number of students with very negative attitudes and intentional behaviours. Investigation as to whether previous experience of autism may be predictive of higher scores was not significant. Many other factors may be at play which were beyond the scope of this investigation. Suggested factors include parental attitudes, peer group influences, cognitive level, inaccurate conceptions of autism and school related factors (de Boer et al., 2012). Being female was predictive of more positive intentional behaviours, especially in the general social category. General social
relates to social activities within the school setting. Gender as a predictor of attitude has mixed reports, with a definite pattern of younger girls showing more positive attitudes, but studies of college students indicating more mixed findings. There are some indicators that older males become more positive and inclusive than females (Nevill & White, 2011). In addition, because the SAQ uses a hypothetical peer who is male, there may be some choices around intentional behaviour which are more reflective of preferences to spend time with male / female as opposed to the consideration of the autistic presentation (Fleva, 2014).

The inclusion of questions relating to neurodiversity is novel to this study and represents an original dimension to perspectives on secondary school students’ attitudes and understanding of autism. The students in this study had little to no awareness of the term ‘neurodiversity’ with only 5.6% (n=4) of students reporting they had heard of the term. A series of questions relating to attitudes to parenting children with autism gave some interesting insights into the samples underlying attitudes. The questions had originally been conceived to demonstrate a dichotomy between attitudes more consistent with a medical model of autism as opposed to a view more in keeping with the neurodiversity movement and a biopsychosocial perspective. For this sample as they had little awareness of neurodiversity, their answers give some insight into their underlying attitude towards autism as a deficit or difference. For the majority of students, they indicated that parents should accept autism as part of their child’s identity, but also teach their child to develop skills and try and find out what caused their autism. They were less adamant in terms of expectations for their child to be taught to be typical (61.1%) or seeking a cure (61.1%). These replicates findings in the general population reported by Kapp et al. (2013).
Students with previous experience of autism were less likely to believe parents should seek a cure for their child with autism. This is reflective of Kapp et al.’s (2013) findings. Despite not knowing the term neurodiversity, it would appear that those who knew someone with autism may hold values or attitudes closer to a biopsychosocial model of disability / neurodiversity than a more traditional medical model view. Although pitching the two concepts against each other may be unhelpful. This is particularly useful in terms of planning autism acceptance interventions in schools and is informative in terms of pitching and debating inclusivity within a framework such as the WHO ICF (Maxwell, Alves, & Granlund, 2012).

10.5.1 Limitations and Recommendations

This study addresses an important gap in the published literature relating to older secondary school students’ knowledge and attitude towards ASD. Although a measure of autism knowledge was utilised which was assessed as the best option available for this study, psychometric properties were weak (Campbell & Barger, 2011). More probing questions into the students’ actual conceptions of autism may have proved informative. The discrepancy between the relative high levels of knowledge reported and the students’ less informed views on what causes ASD demonstrate this. All the measures were self-report, and in the case of the SAQ in response to a hypothetical peer. It remains unclear if reported attitudes and intentional behaviours transfer into real life. Despite theoretical argument that measures of intentional behaviour reflect actual behaviour, there is little evidence to prove this (Campbell, 2008). The many other social, environmental and participatory barriers within school and adolescent life may mean intentions and actual behaviours differ. It is recommended that methods including behavioural and observational measures which capture actual behaviours may prove
useful in conjunction with self-report measures. The findings from this study also indicate that interventions to improve attitudes and intentional behaviours may also be beneficial, particularly in light of the reported isolation of students with ASD in the secondary school setting. Despite seemingly high levels of knowledge and intentional behaviour, it appears that students need to develop more skills in socially reaching out to their peers with ASD and recognising the challenges to communication and making social connections that having ASD may bring.
11 Chapter Eleven: A Scoping Review of Autism Awareness Interventions for Children and Youth.

11.1 Introduction

International best practice advises that students with ASD be educated in mainstream environments, with appropriate supports alongside their typically developing peers (Parsons, Guldberg, et al., 2009). A key benefit of this is that it will give students the best opportunity to learn alongside and from their peers, with a specific belief that the students will benefit socially (Kim, Koegel, & Koegel, 2017). However, evidence shows that, for many, an inclusive policy does not necessarily mean social inclusion. The literature reports on students with ASD at all ages finding it difficult to make friends, form social networks and establish themselves within the social contexts of schools or colleges, (e.g. Chamberlain et al., 2007; Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011; Lasgaard et al., 2010). Higher incidences of exclusion and bullying are reported for those with ASD than their peers without ASD (Hebron & Humphrey, 2014a; Humphrey & Hebron, 2015; Humphrey & Symes, 2010a). It is suggested that there may be a number of contributing factors to these social challenges. The three main factors presented by Humphrey and Hebron (2015) are characteristic of the student with ASD, the physical context i.e., the school and to others in their social environment i.e., peers.

The core social deficit associated with ASD, as classified by the APA diagnostic criteria, highlights social and communication difficulties (APA, 2013). These difficulties affect students with ASD in terms of interaction, communication and in displaying unusual, restricted and repetitive behaviours which can limit participation in
social and extracurricular activities (Carter et al., 2014; Ormond et al., 2004). The spectrum of difficulty means that these social challenges can vary from subtle difficulties picking up social nuances to very limited speech and communication (Carter et al., 2014).

The context of education, may inadvertently create social barriers for the student with ASD. Despite inclusive policies, students with ASD are often segregated or separated within the school. It has been demonstrated that the presence of a special assistant or teaching aid, can be a barrier to social opportunity (Osborne & Reed, 2011; Symes & Humphrey, 2012). Physical placement of the student in a special class or unit separates them from their mainstream peers, as is frequently the case in the Irish education system (Daly, 2016). Teacher’s attitudes have also been presented as having an effect on social inclusion (Gregor & Campbell, 2001; Segall & Campbell, 2012). In addition, a general lack of support particularly around socialisation and making social contacts can be impactful, and this is often the criticism of third level education settings (White et al., 2016).

The final factor relates to the “hidden” nature of ASD as a disability, as one which is poorly understood by peers. Research applying attribution theory (Juvonen & Weiner, 1993; Ling, Mak, & Cheng, 2010) reported that often the behaviours of students with ASD are misconstrued by their peers. They can reject or attribute negative emotions to students with ASD based on their observation of behaviour, with the assumption that these behaviours are within the control of the person. Campbell et al. (2004) demonstrated that once peers are given explanatory and descriptive information about ASD and an understanding of how it impacts on a student’s skills and behaviours that it can change their perceptions of them. Descriptive information is information that typically highlights similarities between the person with ASD and those without ASD,
and explanatory information includes information about the cause, deficits and presentation of ASD.

Sasson et al. (2017) demonstrated through a scientifically rigorous experiment that observers’ first impressions of children and adults with ASD engaging in social behaviour were significantly less favourable than those of matched neurotypical controls. These less favourable impressions were also associated with reduced intentions to socially engage with the person with ASD. The challenge of a socially reciprocated interaction for a student with ASD is confounded by this.

It is this point which forms the basis for this scoping review. Much has been written about improving the social skills of students with ASD and creating more socially inclusive environments, but very little is known about improving peers’ understanding of ASD. Peers constitute the main aspect of the social world for students with ASD but how they perceive their peers with ASD and if anything can be done to improve this perception is not well understood to date.

This is demonstrated by the Reciprocal Effects Peer Interaction (REPIM) which illustrates in Figure 11.1 how the social challenges of students with ASD are further compounded by a lack of peer understanding and awareness (Humphrey & Symes, 2011 p.4).
The model demonstrates that reduced opportunities for peers to learn about ASD is an important factor in the social challenges students with ASD face.

Carter et al. (2014) highlight approaches focused on peers as a key factor in improving social competence and promoting peer relationships for students with ASD. It is advised that peer focused interventions should incorporate informational efforts, peer training and interactional opportunities. Evidence exists for incorporating explanatory and descriptive information about autism into any intervention, but less is known about how useful teaching direct strategies or training for communication is (Campbell & Barger, 2014; Campbell et al., 2004).

Interventions which develop social awareness in the classroom around a specific child with ASD are reported in the literature such as ‘circle of friends’, (e.g., Frederickson, Warren, & Turner, 2005; Gus, 2000). But these types of intervention do little to educate about the nature of ASD or change perceptions about ASD more
generally (Ezzamel & Bond, 2016). There is a large body of evidence for peer-mediated interventions (PMI), which are considered an evidence-based practice (Chang & Locke, 2016). PMI involve training typical peers to engage with students with ASD with a specific goal or objective of the intervention, usually a social skill. The limitation of many of these studies is that as the objective is skill acquisition for the student with ASD, they rarely address the peers understanding or learning related to ASD (Ezzamel & Bond, 2016). Watkins et al. (2015) provide a comprehensive review of PMI within inclusive settings.

Programmes or interventions which specifically target the knowledge, attitudes or related concepts such as stigma and intentional behaviours of peers’ without ASD are less well researched within the ASD domain. There are mixed reports of interventions relating to disability awareness in school which have measured attitude change and/or acceptance of people with disabilities. A systematic review of these interventions (Lindsay & Edwards, 2013) demonstrated that 34 out of 40 reviewed studies showed statistically significant gains in attitude or acceptance, with a variation in levels of evidence, eight of these studies also demonstrated improved knowledge (Lindsay & Edwards, 2013). Of note only two of the 42 studies applied to ASD. All these studies were very mixed in terms of the interventions offered with huge variation in the components, length, focus and intensity of the programmes (Lindsay & Edwards, 2013).

The current literature review aims to synthesise published research on intervention studies which were designed to specifically improve aspects of autism awareness for children and youth without ASD. Its purpose is to synthesise relevant studies and to examine the characteristics of each study and intervention, including levels of evidence, types of intervention and target populations, and to make recommendations for future developments.
11.2 Method

The current literature review follows the methodological framework of a scoping review as presented by Arksey and O'Malley (2005). A scoping review has five stages: identifying the research questions; identifying relevant studies; study selection; charting the data and collating; summarising, and reporting the results.

The research questions include:

Are educational programmes relating to autism awareness effective in changing students’ knowledge, understanding, attitudes or intentional behaviours?

What is the nature of these intervention programmes?

What recommendations for further development in this area can be deduced?

11.2.1 Search Strategy

Articles were identified for inclusion by conducting comprehensive searches of six electronic databases: Scopus; PsycInfo; Web of Science; ScienceDirect; ERIC, and Psychology & Behavioral Sciences Collection. Searches were carried out by inputting the following key terms:

- autis*, ASD, Asperger*, pervasive developmental disorder, or developmental disability;
- school* or education;
- college or third level or university;
- stigma or attitude or knowledge or ‘intentional behav*’ or understanding or acceptance or awareness;
Limiters used in the search were peer reviewed articles, published between 1997 and 2018 and published in English.

In addition to these electronic searches, a subsequent review of the reference lists of all included studies was conducted by hand in order to identify any other suitable studies for inclusion. This review considered studies that reported on knowledge, attitude, understanding, intentional behaviour and levels of stigma of students without ASD who had participated in an educational programme or intervention about ASD.

Studies with experimental designs including randomised controlled trials, non-randomised controlled trials, quasi-experimental, before and after studies and case control studies were considered for inclusion. Studies were excluded if the outcomes did not describe change in these variables in peers without ASD or if they did not have either a pre-post design or a control group.

Through the search process 158 articles were located. The researcher reviewed these articles’ titles and abstracts based on the inclusion and exclusion criteria. Following this process and the removal of duplicates, 40 articles were included for further analysis. The researcher and two independent reviewers read each of these based on the inclusion and exclusion criteria. Following selection of the eligible articles, they met to agree on any articles that did not have unanimous decision. Out of the 40 articles, 11 were deemed to meet the inclusion criteria for the review.

Common reasons for rejection were: 1) lack of pre-post data or control group; 2) no actual intervention occurred, or 3) only those with ASD were measured post-intervention and not their peers without ASD. For example, Carter, et al. (2016) report on pre- and post-intervention observational data but did not measure change in
knowledge, attitude, understanding, intentional behaviour or levels of stigma of students. Campbell et al. (2011) measured knowledge but there was no intervention provided. Scheil, Bowers-Campbell, and Campbell (2017) describe an intervention without measuring outcomes. Fleva (2014) did not employ a control condition.

11.2.2 Data extraction

The 11 selected studies were then summarised and coded by the researcher in terms of the following characteristics: participants; sample characteristics; study design, measures (dependent variables); theoretical framework; objectives; intervention procedures and type; key findings, and limitations. These characteristics are similar to those used by Lindsay and Edwards (2013) in their review of disability awareness interventions. Table 11.1 presents included study characteristics.

Having described the main characteristics of each study, further analysis was necessary to provide more detail on each study and to assess its quality. The 11 studies were evaluated regarding the intervention and measures utilised. The specific elements of the intervention and measures examined included:

- Type of information delivered to students (descriptive, explanatory and directive);
- Method of intervention administration (e.g., direct contact or otherwise);
- Types of measures (standardised, non-standardised or qualitative);
- Outcome variables;
- Length of the intervention;
- Who delivered the intervention;
- Effectiveness of the intervention;
• Findings reported;
• Reports of social validity.

For evaluation of the quality of the studies the Scientific Merit Rating Scale (SMRS) was considered. The national standards project (NSP) which addresses the need for evidence-based practice guidelines for autism spectrum disorders developed the SMRS, as a means of objectively evaluating the methods used in a study, and of evaluating the strength of these methods (Howard, Ladew, & Pollack, 2009). There are five critical dimensions to the evaluation of research, namely: research design; measurement of the dependent variable; measurement of the independent variable (treatment fidelity); participant ascertainment, and generalization. Although the interventions in the current review were not designed for those with ASD, it was considered that the scale, with some adaptations would be useful in gauging the scientific merit of the published studies, as they contribute to the evidence base relating to ASD specifically. However, on application to the studies it became apparent that the critical dimensions were very specific to participants with ASD, and the specialised intervention for this population, most specifically the participant ascertainment and the measurement of independent variables. Therefore, it could not be applied satisfactorily. The studies were therefore evaluated for their level of evidence based on the more general classification of the American Academy of Neurology’s classification system of evidence for therapeutic intervention (Edlund, Gronseth, So, & Franklin, 2004). Class 1 is a randomised control trial meeting five quality criteria; Class 2 is a randomized control trial meeting all but one of the five quality criteria from Class 1 or a prospective matched cohort study that meets the four applicable criteria in Class 1; Class 3 is all other controlled trials where outcome is independently assessed, or independently
derived by an objective outcome measure, and Class 4 are all other studies not meeting Class 1 to 3 criteria. These classifications are presented in Table 11.1 and details of the classification system are provided in appendix E.

11.3 Results
A total of 11 studies were reviewed and charted according to the characteristics and criteria detailed (see Table 11.1). The intervention and measures are also presented and discussed further according to the headings given in section 11.2.2.
<table>
<thead>
<tr>
<th>Authors and Country</th>
<th>Participants (%female)</th>
<th>Sample Characteristics</th>
<th>Study design</th>
<th>Dependent variable or Measure</th>
<th>Theory base</th>
<th>Objective</th>
<th>Intervention procedure and type</th>
<th>Outcomes/ key findings</th>
<th>Limitation</th>
<th>Classificatio n of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gillespie-Lynch et al., 2015 North America</td>
<td>N= 365 (54.2%)</td>
<td>Mean age 19.9 years</td>
<td>Pre-post design (online)</td>
<td>Social distance scale (stigma)</td>
<td>N/A</td>
<td>To determine if participation in online training about autism was associated with increased knowledge and decreased stigma</td>
<td>Online- self administered 75 PowerPoint slides covering 13 key concepts. Periodic comprehension checks before moving onto next section</td>
<td>Stigma decreased Autism Knowledge increased</td>
<td>Quasi experimental so limited efficacy inferences. No assessment of generalisation or maintenance</td>
<td>Class 4</td>
</tr>
<tr>
<td>Mavropoulou &amp; Sideridis, 2014 North Greece</td>
<td>N= 475 (46.1%)</td>
<td>Mean age 10.97 years</td>
<td>Experimental control group design</td>
<td>Knowledge of Autism</td>
<td>N/A</td>
<td>To measure the effects of contact with integrated students with autism spectrum disorders (ASD) on the knowledge, attitudes and empathy of children from grades 4–6</td>
<td>Contact Weekly contact with a peer with ASD. Teacher led instructions carried out by integrated group in the classroom</td>
<td>Significant positive effects in levels of cognitive attitude, behavioural intention and knowledge of autism Positive findings maintained at three month follow up.</td>
<td>Participants were not randomly allocated. No measure of affective component of attitude. Self-report measures can lead to socially</td>
<td>Class 4</td>
</tr>
</tbody>
</table>
Ranson & Byrne, 2014  
Australia  
N = 273 (100%)  
N = 48 intervention group, median age 13 years  
N = 56 no intervention peer group, median age 13 years  
N = 169 no intervention no peer group, median age 12 years  
Catholic girls school  
Experimental design  
Pre-post control group  
The Autism Knowledge questionnaire  
The Adjective Checklist (Cognitive attitudes)  
The Shared Activities Questionnaire (Behavioural Intentions)  
Similarity Rating Form  
Perceived responsibility Questionnaire  
Student Interaction Questionnaire  
To determine if the knowledge, attitudes and behavioural intentions of students who participated in an educational programme will improve towards female peers with High Functioning Autism (HFA)  
"understanding our peers"  
To determine any spill over effect of the intervention to no intervention peer group.  
Educational Intervention  
Descriptive, explanatory, directive information and contact with individual with HFA  
- rated peers with HFA as significantly more similar to themselves.  
- were able to differentiate between strategies for effectively interacting with peers with HFA  
- increased knowledge about HFA.  
Online activity in web-based learning site as homework  
Self-report measures can lead to socially desirable responses.  
Class 2  
 relativley low student participation rate (45 %)  
participants from Catholic schools that explicitly place value on messages of social justice

<table>
<thead>
<tr>
<th>Basic Empathy scale (Empathy)</th>
<th>Short educational intervention prior to entry of peer with ASD to the classroom</th>
<th>desirable responses.</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>In post test the Intervention group</td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>-rated peers with HFA as significantly more similar to themselves.</td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>-were able to differentiate between strategies for effectively interacting with peers with HFA</td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>- increased knowledge about HFA.</td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>-demonstrated significant effect on attitudes towards peers with HFA, also shown no intervention peer group</td>
<td></td>
</tr>
</tbody>
</table>

In post test the Intervention group
- rated peers with HFA as significantly more similar to themselves.
- were able to differentiate between strategies for effectively interacting with peers with HFA.
- increased knowledge about HFA.
- demonstrated significant effect on attitudes towards peers with HFA, also shown no intervention peer group.
had marginally better behavioural intentions towards peers with HFA, but not maintained into following term.

Staniland & Byrne, 2013
Australia

- To determine if the knowledge, attitudes and behavioural intentions of students who participated in an educational programme will improve towards male peers with High Functioning Autism (HFA)
- To determine any spill over effect of the intervention to no intervention peer group

Experimental design
Pre-post control group

The Autism Knowledge questionnaire
The Adjective Checklist (Cognitive attitudes)
The Shared Activities Questionnaire (Behavioural intentions)
Similarity Rating Form
Perceived responsibility Questionnaire
Student Interaction Questionnaire

Educational Intervention
Descriptive, explanatory, directive information and contact with individual with HFA “understanding our peers”
Online activity in web-based learning site as homework

In post test the Intervention group - rated peers with HFA as significantly more similar to themselves.
- were able to differentiate between their peers with HFA and no intervention peer group.
- demonstrated significant effect on knowledge about HFA,
- increased knowledge about strategies for interacting effectively with peers with HFA.

Participants
All male and from middle class background

Difficulties with randomization
Self-report measures can lead to socially desirable responses
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Population</th>
<th>Design</th>
<th>Measures</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obeid et al., 2015</td>
<td>N=675 (62.7%)</td>
<td>USA: N = 346, mean age = 18.4 years Lebanon: N = 329, mean age = 18.4 years, Undergraduates</td>
<td>quasi-experimental design</td>
<td>Social distance scale (stigma) Online- self administered 75 PowerPoint slides covering 13 key concepts. Periodic comprehension checks before moving onto next section</td>
<td>To determine if participation in online training about autism was associated with increased knowledge and decreased stigma amongst college students in the USA and Lebanon to evaluate the cross-cultural effectiveness of an online training about ASD</td>
<td>Increase in knowledge and decrease in stigma in both populations. Stigma remained higher in Lebanon than USA after and before training. Quasi experimental so limited efficacy inferences. No assessment of generalisation or maintenance. Attrition rates higher in Lebanon than USA.</td>
</tr>
</tbody>
</table>
| Silton & Fogel, 2012         | N=158 (47.5%) | students from 4th, 5th and 6th grade. Mean age = 10.39 76.6% had previous exposure to ASD | Experimental design | Shared activities questionnaire (behavioural intention) Cognitive Consistency Theory (Heider 1958) Social Attribution Theory (Heider 1958, Kelley 1967) Adjective checklist (cognitive attitude) | Brief video intervention Video 1 – descriptive and explanatory information about autism Video 2,3,4 - descriptive and explanatory information about autism | Participants in all video conditions showed significant gains in behavioural intentions. Peer strategies conditions showed the highest and most positive scores on | Small sample size, all attended Jewish day schools so homogenous sample. Self-report measures can lead to socially
<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Setting</th>
<th>Methods</th>
<th>Interventions</th>
<th>Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ezzamel &amp; Bond, 2017 UK</td>
<td>N=7 (35%)</td>
<td>Mainstream primary school in Northwest England</td>
<td>Mixed methods</td>
<td>Playground observations – adaptation of Playground Observation of Pupil-Peer Engagement (POPE)</td>
<td>To determine the impact and how pupils with ASD and peers perceive participating in a peer network intervention</td>
<td>No no-intervention control group Video intervention with child actors who may not have displayed ASD accurately.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Year 3</td>
<td>Interviews</td>
<td></td>
<td>Two whole class awareness sessions (n=18)</td>
<td>No quantitative measure of attitude change No follow up No inter-rater checks on observation data</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Focus group</td>
<td></td>
<td>Enjoyed the group</td>
<td>Small sample with limited generalisation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Learnt new skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Gained understanding and acceptance of needs of child with ASD</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Number of occasions peers responded appropriately to child with ASD</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>initiated increases</td>
<td></td>
</tr>
</tbody>
</table>

| Reiter & Vitani, 2007 Israel              | N=23 (47.82%)  | 1 class in Kibbutz school northern Israel                              | Pilot study Pre-post design                                                                       | Burnout questionnaire Mediated Learning (Feuerstein et al. 1991)            | To determine the extent of which negative attitudes held by regular pupils towards their peers with autism correlated | Significant negative relation between the behavioural and affective measures and burnout on the |
|                                          |                | Age range 9 to 10 years                                                |                                                                                                   |                                                                            | Mediated learning 19, 60-minute sessions once a week.                      | No no-control group                                                       |
|                                          |                |                                                                        |                                                                                                   |                                                                            |                                                                            | Small sample size                                                          |
Quality of Mediation Questionnaire

CATCH scale (attitude)

To determine whether an intervention program based on mediated learning improved the quality of mediation by the regular pupils and had a positive effect on their attitudes towards their peers with autism.

fatigue and lack of self-fulfilment scales

Homogenous group

Significant difference on each of the attitude questionnaire subscales between the pupils’ attitudes towards their peers with ASD before and after program except on the cognitive measure.

Self-report measures can lead to socially desirable responses

No follow up

Swaim & Morgan, 2001
USA
N=233 (50%)
3rd grade, mean age = 9.12 years and 6th grade, mean age 12.02 years
3 conditions: No ASD (n=78), ASD (n=77), ASD and information (n=78)

Analog study
Experimental design

Adjective checklist (Cognitive attitude)
Shared activity questionnaire (Behavioural intentions)
Similarity Rating Form

Social desirability and Attribution theory

To examine the attitudes and intentional behaviours of children towards their peers with and without ASD

3 video conditions
- no autism
- autism
- autism and information

Less positive attitude towards peer with autism

6th grade and females gave lower activity rating to child with autism than typical peer.

Information explaining autism had no effect on attitude or behavioural intention.

No pre-post measures

Class 3

Campbell et al., 2004
N=576(48.96%)
Mean age 10.06
Analog study
Experimental design

Adjective checklist
Attribution theory

To examine the effects of a brief video intervention using descriptive

Video vignette with explanatory and descriptive

Less positive attitude towards peer with autism

No pre-post measures

Class 3
<table>
<thead>
<tr>
<th>USA</th>
<th>3rd, 4th and 5th grade</th>
<th>(Cognitive attitude) and explanatory information about ASD on attitudes and behavioural intentions.</th>
<th>Combination of descriptive and explanatory information resulted in improved cognitive attitudes for 3rd and 4th grade but not 5th grade.</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1% had heard of ASD</td>
<td>Shared activity questionnaire (Behavioural intentions) – short format</td>
<td>Similarity Rating Form</td>
<td>Descriptive and explanatory information improved overall intention to engage in shared behaviours.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Video intervention with child actors who may not have displayed ASD accurately.</td>
</tr>
<tr>
<td>Tonnsen &amp; Hahn, 2016</td>
<td>N=78 (46.43)</td>
<td>To examine how middle school students' attitudes to a fictional pee with ASD varied according to physical inclusion and social acceptance.</td>
<td>Social acceptance but not physical inclusion predicted highest reported attitude</td>
</tr>
<tr>
<td>USA</td>
<td>Mean age 12.38</td>
<td>Online video blog - Six conditions</td>
<td>ASD diagnosis elicited more negative attitudes</td>
</tr>
<tr>
<td>Grades 5 to 7</td>
<td>Analog study</td>
<td></td>
<td>Video intervention with child actors who may not have displayed ASD accurately.</td>
</tr>
<tr>
<td>CATCH – self and other Adjective checklist (cognitive attitude) Demographic checklist</td>
<td>N/A</td>
<td></td>
<td>Homogenous participant group.</td>
</tr>
<tr>
<td>Experimental design</td>
<td></td>
<td></td>
<td>No manipulation check</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Class 3</td>
</tr>
</tbody>
</table>
physically included

control accepted
socially—
physically included

control rejected
socially—
physically included
11.3.1 Intervention and Measures

All of the included studies described their intervention procedures and measures in detail. It is noted that the intervention used in Gillespie-Lynch et al. (2015) and Obeid et al. (2015) was the same. For Staniland and Byrne (2013) and Ranson and Byrne (2014) the intervention was also similar with some changes made to the latter study. The video intervention used by Campbell et al. (2004), Silton and Fogel (2012) and Swaim and Morgan (2001) was also based on the same concept with adjustments made according to the study condition.

11.3.1.1 Type of information delivered to students (descriptive, explanatory and directive)

Ten of the studies reported on the type of information the intervention delivered. Reiter and Vitani (2007) did not describe the type of information delivered, as the intervention was related to improving mediation between students with and without ASD (Reiter & Vitani, 2007). The intervention delivered by Gillespie-Lynch et al. (2015) and Obeid et al. (2015) was comprised of descriptive and explanatory information relating to current research about autism across the lifespan including definitions of ASD, identification, prevalence, causes, intervention, strengths and challenges faced and views of the neurodiversity movement. The Australian studies delivered descriptive, explanatory and directive information which was specific to High Functioning Autism (HFA) (Ranson & Byrne, 2014; Staniland & Byrne, 2013). Three of the studies compared the effect of different types of information so there were variations in the type of information delivered although all interventions except for control conditions were inclusive of descriptive and / or explanatory information (Campbell et al., 2004; Swaim & Morgan, 2001), with the addition of directive or peer strategies in one intervention and
information about strengths of ASD in two (Silton & Fogel, 2012). Explanatory, descriptive and directive information was incorporated into the UK based study (Ezzamel & Bond, 2017). The video blog described by Tonnsen and Hahn (2016) provided some explanatory information, but it is not explained any further. Similarly, Mavropoulou and Sideridis (2014) describe a short explanatory session prior to their integration project.

11.3.1.2 Method of intervention administration

The interventions for college students in the US and Lebanon was delivered online as 71 PowerPoint slides. There was no contact or in person delivery (Gillespie-Lynch et al., 2015; Obeid et al., 2015). For the two Australian studies, the intervention was delivered in the school setting as an education programme supplemented by web-based learning. One session included an invited speaker with HFA, and video material of people with HFA (Ranson & Byrne, 2014; Staniland & Byrne, 2013). The study based in Israel taught mediated learning strategies to students without ASD, sessions included promoting group cohesion, experiential learning through role play of inclusion, presentation, simulation, modelling and practice of mediation and discussion (Reiter & Vitani, 2007). All the students also had inclusive opportunities with pupils in special ASD class to carry out theses mediated learning strategies. Four of the studies delivered material which was video-based, with child actors playing boy and girl with ASD. For three of these studies the actors did not have ASD (Campbell et al., 2004; Silton & Fogel, 2012; Swaim & Morgan, 2001). The other study reported that the actor had a diagnosis of ASD (Tonnsen & Hahn, 2016). There was no contact with students with ASD in these interventions. Ezzamel and Bond (2017) included whole class awareness sessions, small group peer network sessions and contact with one child with ASD.
Although the terms autism or ASD were not used during sessions due to child with ASD being unaware of his diagnosis. In total only five of the studies incorporated actual contact with a peer or student with ASD, and in two studies this was a once off presentation (Ranson & Byrne, 2014; Staniland & Byrne, 2013). In another, it was with one child and the peers were not aware of his actual diagnosis (Ezzamel & Bond, 2017), and in two it was part of a program of integration with a number of peers (Mavropoulou & Sideridis, 2014; Reiter & Vitani, 2007).

### 11.3.1.3 Types of measures

The most common administered measure of change included in seven studies was the Adjective Checklist (Siperstein, 1980). The measure assesses self-reported cognitive attitude towards a hypothetical target child (with ASD in these studies) by looking at the number of positive and negative adjectives attributed to them (Campbell et al., 2004; Mavropoulou & Sideridis, 2014; Ranson & Byrne, 2014; Silton & Fogel, 2012; Staniland & Byrne, 2013; Swaim & Morgan, 2001; Tonnsen & Hahn, 2016). Six studies used the Shared Activity Questionnaire (SAQ) (Morgan et al., 1996), The SAQ is another self-report scale which assesses intentional behaviour to share academic, active recreational and general social activities with a hypothetical peer with a disability (in this case ASD) (Campbell et al., 2004; Mavropoulou & Sideridis, 2014; Ranson & Byrne, 2014; Silton & Fogel, 2012; Staniland & Byrne, 2013; Swaim & Morgan, 2001). The Chedoke-McMaster Attitudes Towards Children with Handicaps Scale (CATCH) (Rosenbaum, Armstrong, & King, 1986) was utilised in two studies. The CATCH is a 40 item self-report scale of general attitude towards children with disabilities (Reiter & Vitani, 2007; Tonnsen & Hahn, 2016). Qualitative measures featured in three studies (Ranson & Byrne, 2014; Staniland & Byrne, 2013), with only one using face to face
interview technique (Ezzamel & Bond, 2017). One study employed an observational scale, the Playground Observation of Pupil-Peer Engagement (POPE) (Kasari, Rotheram-Fuller, & Locke, 2005) (Ezzamel & Bond, 2017). Five studies measured knowledge of ASD. Gillespie-Lynch et al. (2015) and Obeid et al. (2015) utilised adapted versions of the autism awareness survey (Stone & Rosenbaum, 1988), the two Australian studies devised a bespoke measure and the Greek study used the knowledge of autism questionnaire (KAQ) (Ross & Cuskelley, 2006). Two studies reported on a measure of stigma, which was adapted by Gillespie-Lynch et al. (2015) from the Social Distance Scale (Bogardus, 1933) in relation to college students’ willingness to engage with people with ASD at varying levels of intimacy. Other measures were reported which were either developed for the intervention specifically or measured aspects unrelated to attitude, intentional behaviour or knowledge. Many of the authors acknowledged the risk of socially desirable responses on self-report measures, and in two instances employed second versions of the self-report measure to ask how ‘others’ might view the hypothetical child (Swaim & Morgan, 2001; Tonnsen & Hahn, 2016).

11.3.1.4 Outcome variables

As inclusion criterion was that the studies should measure variables relating to knowledge, attitude, behavioural intention and related concepts in the students without ASD, all the studies measured attitude, except for Ezzamel and Bond (2017), who took a qualitative approach, and reported on perceptions and acceptance. Six studies specifically measured intentional behaviour, five measured knowledge and two measured stigma as outcome variables. One study specifically examined country as a variable, comparing college students after an online intervention in the USA and Lebanon (Gillespie-Lynch et al., 2015). The study by Mavropoulou and Sideridis
specifically examined contact with peers with ASD as a variable in changing attitude and intentional behaviour. Three studies focused on how information was delivered as a variable in influencing attitude and intentional behaviour (Campbell et al., 2004; Silton & Fogel, 2012; Swaim & Morgan, 2001). Reiter and Vitani (2007) examined burnout as a variable in contact sessions with peers with ASD. Physical inclusion and social acceptance were examined as influencing variables in peers’ attitudes towards ASD in Tonnsen and Hahn (2016). Gender and / or age as influencing variables were also examined by seven of the studies (Campbell et al., 2004; Gillespie-Lynch et al., 2015; Mavropoulou & Sideridis, 2014; Obeid et al., 2015; Ranson & Byrne, 2014; Silton & Fogel, 2012; Staniland & Byrne, 2013; Swaim & Morgan, 2001; Tonnsen & Hahn, 2016).

11.3.1.5 Length of the intervention

The length of interventions varied widely from one-off sessions to 19 weeks. The shortest interventions were the video-based intervention lasting between 2 minutes and 22 minutes (Campbell et al., 2004; Silton & Fogel, 2012; Swaim & Morgan, 2001). The online training and video blog were viewed at the students’ own pace but reported to last approximately one hour (Gillespie-Lynch et al., 2015; Obeid et al., 2015; Tonnsen & Hahn, 2016). The Australian studies comprised of six 50-minute class length sessions, inclusive of data collecting (Staniland & Byrne, 2013) and eight 50-minute class length sessions, inclusive of data collecting. (Ranson & Byrne, 2014). Ranson and Byrne (2014) added two additional sessions and enhanced web-based content with incentive to engage to their intervention. The mediated learning strategies were taught over 10 class sessions (60 minutes in length) (Reiter & Vitani, 2007). Ezzamel and Bond (2017) utilised two full class sessions and six small group sessions. (Ezzamel &
Bond, 2017). Mavropoulou and Sideridis (2014) did not report on intervention length, but contact sessions appear to have happened over a school term, with one class period being utilised for an education about ASD session prior to the contact sessions commencing.

### 11.3.1.6 Delivery of intervention

For all of the included studies the intervention was either designed and / or delivered by the researcher. Some also included the assistance of a teaching assistant or expert in the area (Ezzamel & Bond, 2017; Reiter & Vitani, 2007). For on-line and video interventions there was no personal delivery of content (Campbell et al., 2004; Silton & Fogel, 2012; Swaim & Morgan, 2001).

### 11.3.1.7 Effectiveness of the intervention

Effectiveness of the interventions is summarised in relation to the variables of attitude / stigma, intentional behaviour and knowledge and presented in Table 11.2. Only Campbell et al. (2004) reported effect sizes (cohen’s d), so effect is reported if statistical significance was demonstrated. As the studies varied in design, effect is reported with regard to intervention effect on the intervention group in control studies or pre-post measures.
### Table 11.2 Effectiveness of Intervention

<table>
<thead>
<tr>
<th>Author</th>
<th>Knowledge</th>
<th>Attitude / Stigma</th>
<th>Behavioural Intention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campbell et al., 2004</td>
<td>n/a</td>
<td>For descriptive and explanatory – more positive for 3rd (d=.42) and 4th grade (d=.51) not 5th grade</td>
<td>For descriptive and explanatory – Increase (d=.27)</td>
</tr>
<tr>
<td>Ezzamel &amp; Bond, 2017</td>
<td>n/a</td>
<td>More positive (qualitative)</td>
<td>n/a</td>
</tr>
<tr>
<td>Gillespie-Lynch et al., 2015</td>
<td>Increased (p&lt;.001)</td>
<td>lower stigma (p&lt;.001)</td>
<td>n/a</td>
</tr>
<tr>
<td>Mavropoulou &amp; Sideridis, 2014</td>
<td>Increased (p&lt;.05)</td>
<td>more positive (p&lt;.05)</td>
<td>Increased for academic and social (p&lt;.05)</td>
</tr>
<tr>
<td>Obeid et al., 2015</td>
<td>Increased (p&lt;.001)</td>
<td>lower stigma (p&lt;.001)</td>
<td>n/a</td>
</tr>
<tr>
<td>Ranson &amp; Byrne, 2014</td>
<td>Increased (p&lt;.001)</td>
<td>more positive (p=.05)</td>
<td>no significant effect (p=.44)</td>
</tr>
<tr>
<td>Reiter &amp; Vitani, 2007</td>
<td>n/a</td>
<td>more positive (p&lt;.001)</td>
<td>n/a</td>
</tr>
<tr>
<td>Silton &amp; Fogel, 2012</td>
<td>n/a</td>
<td>no effect (p=.26)</td>
<td>Increase for total (p=.034) and recreational (p=.029)</td>
</tr>
<tr>
<td>Staniland &amp; Byrne, 2013</td>
<td>Increased (p&lt;.001)</td>
<td>more positive (p=.01)</td>
<td>no significant effect (p=.37)</td>
</tr>
<tr>
<td>Swaim &amp; Morgan, 2001</td>
<td>n/a</td>
<td>more positive (p&lt;.005)</td>
<td>no significant effect</td>
</tr>
<tr>
<td>Tonnsen &amp; Hahn, 2016</td>
<td>n/a</td>
<td>no effect</td>
<td>n/a</td>
</tr>
</tbody>
</table>

**11.3.1.8 Findings reported**

Other outcomes reported related to additional variables measured. There were mixed findings related to gender and age, with some evidence that girls had slightly higher behavioural intentions and attitude in Campbell et al. (2004) and Tonnsen and Hahn.
but no other study which assessed gender as a variable. Younger children also appeared to have more positive attitudes and behavioural intentions in three studies (Campbell et al., 2004; Swaim & Morgan, 2001; Tonnsen & Hahn, 2016). In Obeid et al. (2015) stigma and knowledge was lower for students from Lebanon compared to the USA post-intervention. In terms of information type, Campbell et al. (2004) demonstrated descriptive and explanatory information were superior to descriptive alone. Silton and Fogel (2012) demonstrated the most positive findings for behavioural intentions when explanatory, descriptive, strategies and strengths information were given.

11.3.1.9 Social validity or feedback

For the majority of studies there was no reference to feedback from participants or attempts to examine feasibility of implementing the intervention again. Ezzamel and Bond (2017) report qualitative perceptions of teachers and peers, as a large part of their study involved staff and students’ perceptions of the intervention. Feedback was positive, with some concerns about the use of terminology and training required in order to implement the program independently. A qualitative feedback survey is referred to by Ranson and Byrne (2014), but findings were not reported.

11.4 Discussion

This review delivers the evidence base for and description of published research on intervention studies which were designed to specifically improve aspects of autism awareness for children and youth without ASD. It indicates the dearth of research in this area, and a limited evidence base for the interventions. The mix of intervention types, methods and measures also makes it challenging to draw any overall conclusions.
Although all the studies did set about similarly to examine knowledge, attitude or intentional behaviour change, with a view to improving the inclusive experiences of students with ASD, it is also acknowledged within the studies that peers only form a part of efforts to improve inclusion and many other interventions exist which have demonstrated improved social experiences for students with ASD, without addressing knowledge or attitudes (e.g., Carter, et al., 2016).

In terms of the interventions presented, there was a notable variety, particularly in terms of the length of intervention. It is suggested in disability acceptance programmes that longer interventions are more effective (Rillotta & Nettelbeck, 2007), but there was no comparison made in the studies reviewed. Common elements related to the provision of descriptive and explanatory information, which was found to be more impactful than just one type of information. Despite different delivery methods such as video, online or in person the interventions did effect change on knowledge and attitude. However behavioural intention was less well effected, with aspects of behavioural intention reported to improve by Silton and Fogel (2012) when additional information related to strengths and directive strategies was introduced, and in the largest sample size study which measured these variables (Campbell et al., 2004). The other study which changed behavioural intention scores was the intervention which has prolonged contact (but little information / education) (Mavropoulou & Sideridis, 2014). It could be concluded that a combination of all these aspects may be the most useful, i.e., descriptive, explanatory, directive and contact. Lindsay and Edwards (2013) in their review of disability awareness interventions similarly report social contact as a component of a successful intervention and conclude by recommending multiple-components and interactive elements to them.
The cultural, gender and age diversity to the interventions reviewed is also highlighted. More successful interventions tended to be with older students. It is suggested that more disability specific and detailed programmes have greater impact on older students (Lindsay & Edwards, 2013). Gender did not appear to be an influencing factor on outcomes, although girls were reported to have better pre-intervention attitudes in some studies. The socio-cultural context of the studies challenges comparisons also. Obeid et al. (2015) study indicated the cultural differences in knowledge and attitude, but also demonstrated culture did not influence learning. Three of the intervention appeared to relate specifically to the socio-cultural context and would be difficult to transfer into other settings (Mavropoulou & Sideridis, 2014; Reiter & Vitani, 2007; Silton & Fogel, 2012).

11.5 Conclusion

This review addressed a gap in the knowledge base and literature in relation to evidence for autism awareness programs for young people. Despite recommendations that these types of intervention be implemented to improve the social inclusion landscape for students with ASD, there has been shown to be a paucity of studies in the area (Bellini, 2006; Humphrey & Symes, 2011). It is clear from the current literature review that those which have been carried out vary greatly in terms of quality and outcomes. There is some emerging evidence for their effectiveness in changing knowledge, attitude and intentional behaviours of students without ASD. However, this is a small pool of studies to inform the most effective component elements of the interventions, or length or type of delivery. Analyses indicate that multiple components, with interactive and contact elements are positive to an intervention. It should be noted however that due to the limitations of sample sizes, the wide variety of ages, cultures and interventions, it is very difficult to form any resolute conclusions.
Future research should employ more rigorous designs with interventions implemented across multiple sites. Researchers should also consider the socio-cultural context, the length of intervention and contact with students with ASD.
12 Chapter Twelve: Project ALLY – an intervention to improve knowledge and understanding of ASD

12.1 Introduction

Despite findings of neutral to high self-reported attitudes to ASD (de Boer, Pijl, and Minnaert, 2012), and high levels of knowledge (Carter et al., 2008) in the literature and chapter ten of this study, interactions amongst students with and without ASD remain infrequent in school settings (Campbell & Barger, 2014; Carter et al., 2008; Locke et al., 2010). There is a need for strategies and interventions to transfer positive attitudes towards interaction amongst students with and without ASD.

The results of the review conducted in chapter 11 demonstrate that there is a lack of quality published intervention research to date addressing concepts relating to students without ASD understanding, interacting and accepting of their peers with ASD. Developing acceptance and awareness of ASD is recognised as a key factor in improving students’ experience of school and quality of life in adults with autism (Cage et al., 2017; Humphrey & Symes, 2011).

Developing understanding of ASD in secondary school settings is alluded to by Humphrey and Symes (2011) as a “two-pronged approach” (p.414), which targets both students with ASD and their peers. Their Reciprocal Effects Peer Interaction Model (REPIM) demonstrates how students with ASD social challenges are further compounded by a lack of peer understanding and awareness (Humphrey & Symes, 2011). In essence the model represents how poor-quality peer interactions and lack of social networks leads to reduced motivation for social contact and solitary behaviour for
those with ASD, but also reduced opportunities for those without ASD to learn about ASD and therefore accept those with ASD (Humphrey & Symes, 2011). Their suggestion is to sensitively improve understanding of autism, acceptance of difference and provide guidance about how to positively communicate with peers with ASD. This suggestion formulates the conception of the intervention which will be evaluated in this study.

12.1.1 Autism Acceptance

Autism acceptance is defined by Cage et al. (2017) as “an individual feeling accepted or appreciated as an autistic person, with autism positively recognised and accepted by others and the self as an integral part of that individual” (p.474). Using a social model of disability it is proposed that autism acceptance could be a predictive factor in mental health outcomes for individuals with autism. Cage et al. (2017) found adults with autism reported levels of societal acceptance of autism correlated with depression. Their research advocates that support and acceptance by others can be preventative of depression in adults with autism. Although requiring more investigation, it does make sense that a more accepting and informed society can lessen risks for depression and other mental health difficulties in those with autism. This further emphasises the importance of educating adolescence about autism and autism acceptance in a general sense, as well as interventions which directly relate to peers with autism in their school setting. With specific reference to adolescence, Lasgaard et al. (2010) found that perceived social support from family and peers was negatively correlated with loneliness in adolescence with autism.

Part of the challenge to autism acceptance is that for many adolescents with autism, they may not identify as autistic, or may be struggling with autism as part of
their identity formation (Cage, Bird, & Pellicano, 2016). Outside of the scope of this study, it remains an issue which researchers and educators need to address, particularly if education around autism acceptance becomes more prevalent in secondary school settings.

12.1.2 Peer Focused Educational Programmes

Peer focused educational programmes attend to attitudinal and knowledge barriers to peer relationships, however it is recognised that information alone is rarely sufficient to shift social barriers between peers (Carter et al., 2014). It is recommended that peers be trained in interaction approaches and conversational strategies that will enable peers to become more confident and effective in their interactions with peers with ASD (Carter et al., 2014; Carter et al., 2013). Alongside information, directive strategies are also viewed to be an important aspect to encouraging interactions. With these interactive or communication strategies social or interaction opportunities also need to be facilitated (Carter et al., 2014). It can be deduced that ideally an education programme would have three aspects to it including:

- Information about autism (explanatory and descriptive);
- Directive strategies for communication and interaction;
- Contact or social opportunities between peers.

Findings from the literature review reported in Chapter 11 also indicate this multi-component approach is strongest.

12.1.3 Information
When giving information about ASD Campbell (2004) suggests considering the source of information, the message being given and the audience be considered.

The source of the information refers to the provider of information. There is some evidence that credibility of source is important for those receiving information. Older elementary school students receiving information about autism responded more favourably to it being delivered by a professional (Morton & Campbell, 2008).

The message being given, meaning what is being said and how it is delivered. Again, Campbell and colleagues are the source of any research relating to this. The message can be delivered in a descriptive and explanatory way. Attribution theory (Juvonen & Weiner, 1993) and Campbell’s work indicate that explanatory and descriptive messages are more effective than description alone e.g., explaining why a peer may have difficulty with eye contact as opposed to just describing a difficulty with eye contact (Campbell et al., 2004). It has also been shown that drawing comparisons and demonstrating similarities between peers with and without ASD is a useful way of describing the condition. It is unknown if directive messages are useful, although they are often included in peer education programs, and certainly form the major part of many peer mediated interventions. This is where a peer is given direction in to how to carry out a specific activity, such as starting a conversation or helping them with a task. However, these interventions are systematically implemented with careful individualised approach, somewhat different to group based more general directive information.

Finally considering the audience, those who are receiving the information, it is important to consider influencing factors such as gender of participants, their cognitive abilities and age. It is also advised to have a baseline understanding of the participants.
prior experience and knowledge of autism and how this may influence their participation in the educational programme (Campbell & Barger, 2014).

Information provided in an autism acceptance intervention can be described as descriptive and explanatory. Campbell et al. (2004) found that for primary school-aged children, a combination of descriptive and exploratory information was most powerful in changing attitude and intentional behaviour.

### 12.1.4 Directive Strategies

Teaching directive communication strategies is recommended by Carter et al. (2014). Many studies focus on teaching peers techniques to facilitate the communication and interaction skills of those with ASD (e.g., Bambara, Cole, Kunsch, Tsai, & Ayad, 2016; Kasari et al., 2011; Kasari et al., 2012). Peer mediated approaches (PMI) have been well researched and have reported success in improving social and communication skills of children with ASD. For example, Kamps et al. (2015) report positive outcomes for kindergarten and 1st grade children with ASD from a peer network intervention. Far less studies have been carried out with secondary school aged children, but equally show promising results (Asmus et al., 2017; Bambara et al., 2016). Peer mediated interventions are considered to be an evidence-based practice by the National Autism Centre (Center, 2011). For many PMI which use peer partners or networks, students who volunteer and are deemed to be good social models are utilised (Bambara et al., 2016)

These peers are taught strategies for social interaction, which are systematically utilised with selected students with ASD (Carter et al., 2014). PMI usually involve individualised approaches, particularly in relation to prompting and reinforcing. The feasibility for implementation can be challenging, and there is a
requirement for expertise for implementation and measurement (Carter & Pesko, 2008). Peers generally report satisfaction in participating in the intervention, but outside of their satisfaction with participation, little is known about what they learn in relation to ASD or if it impacts on their attitudes or intent to initiate interactions outside of the intervention.

Looking outside of the peers who are chosen for their good social or conversational skills, there may be many others within the school context who do not have strategies or confidence in their ability to communicate with students with ASD, it stands to reason these students would be less likely to instigate a social interaction. PMI as a method for improving social inclusion or autism acceptance may leave many behind, but aspects of it are considered in the design of the intervention for this study as directive strategies.

12.1.5 Contact

There has also been discussion within the field of ASD and more generally around disability awareness programmes in schools as to the impact of contact with individuals with autism (or the designated stigmatised condition) as an element of the intervention. A comprehensive systematic review concludes that extended contact and contact as part of intervention are more effective than programmes without contact. Those without contact demonstrated small to no effect sizes (Armstrong, Morris, Abraham, Ukoumunne, & Tarrant, 2016). Therefore, contact as a component of an educational programme has been demonstrated to be effective for ‘non-disabled’ peers, but contact may not be so useful for the students with autism if it is without purpose or direction. Bambara et al’s (2016) study relating to improving conversational skills in high school students with ASD demonstrated that just providing opportunities for social interaction
between students with ASD and peers without an intervention made for ‘strained and awkward conversations.

On the one hand PMI are not inclusive of a majority of peers and have limited known effects on improving autism acceptance, knowledge or understanding. On the other hand, providing contact or social interaction opportunities for improving understanding of autism, may have limited value to the students with autism. This study sought to marry the two by providing directive information to the participating peers about communication strategies, including general guidelines around prompting and reinforcing communication with the students with ASD, whilst also giving both sets of students to opportunity to interact and make social connections in a structured setting.

12.1.6 Other factors
Other important factors in designing educational programmes are length of programme, size of the intervention group and feasibility of implementation in the school setting. The length of interventions reported in the literature varies hugely from one very short video-based session to interventions which take place over the whole school year. It would appear that multi-session interventions may be more effective (Ranson & Byrne, 2014; Staniland & Byrne, 2013). There is evidence that smaller groups have higher impact on social interactions particularly (Carter et al., 2008).

12.1.7 Project ALLY – Autism and Lasting Links for Youth
This exploratory randomised control study aimed to evaluate the effects of an autism acceptance intervention for transition year students over nine sessions. The intervention named ‘Project ALLY’, aimed to address knowledge of ASD, attitude, intentional behaviours of students towards those with ASD and concepts of
neurodiversity, through a specifically designed educational intervention for this purpose. The intervention is inclusive of structured interactive contact opportunities with students with ASD.

Project ALLY used descriptive, explanatory, directive and experiential methods to achieve this. Project ALLY was inclusive of students accessing ASD classrooms in the secondary schools for three of the nine sessions. This experiential contact element is a distinctive feature of the intervention.

The study aimed to evaluate the effects of Project ALLY on student self-report measures of knowledge of autism, attitude towards those with autism, intentional behaviours towards a hypothetical peer with autism and concepts of neurodiversity. It also aimed to assess learning specific to the intervention content. The study also gathered feedback from participants in the intervention and students in the ASD classes who took part in joint sessions in order to establish social validity for the intervention.

12.2 Method

12.2.1 Participants

Participants were 72 transition year students who attended two mainstream co-educational secondary schools in the Leinster region of Ireland. This is the same group who participated in the study presented in Chapter 11.

Both schools had ASD classrooms, with seven students in each. None of these students were in transition year. These students attended classes in these special classrooms, some also remained there during lunch and break times. All these students also attended some classes in the mainstream school. These students were given information about the study to bring home to their parents. They were invited to join in three joint sessions
with transition year students. All their parents consented, and they assented to joining in the sessions and completing feedback on the group.

In each school, transition year students were given information about the study and parental consent forms by a member of staff, this was a total of 77 students, which represented three class groupings. Seventy-two transition year students agreed to participate in the study. Three participants in the second school control group missed the data collection for post intervention. The final number for both groups was N=72, with n = 36 receiving the educational intervention and n = 36 acting as controls. All the students were mainstream transition year students aged between 15 and 16 years.

Table 12.1 Study Participants (n = 72)

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>40</td>
<td>55.6</td>
</tr>
<tr>
<td>Female</td>
<td>32</td>
<td>44.4</td>
</tr>
<tr>
<td><strong>Experience of autism</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>36</td>
<td>50</td>
</tr>
<tr>
<td>No</td>
<td>36</td>
<td>50</td>
</tr>
<tr>
<td><strong>Study Group</strong></td>
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<td></td>
</tr>
<tr>
<td>Intervention</td>
<td>36</td>
<td>50</td>
</tr>
<tr>
<td>Control</td>
<td>36</td>
<td>50</td>
</tr>
</tbody>
</table>

12.2.2 Materials - Project ALLY

Project ALLY was devised and delivered by the researcher. The intervention material was prepared as PowerPoint slides with supplementary video material, hand-outs and work sheets. This section provides detail on the theoretical construction of the project, its delivery and outline of content. Further information can be found in Appendix C.
12.2.2.1 Theoretical Construction

Project ALLY was devised based on the recommendations in the research for more investigations of interventions which educate peers about autism (Humphrey & Symes, 2010a). Project ALLY was developed according to the evidence base with particular consideration for Campbell’s research contributions to the theory base. It was designed to include both descriptive and explanatory information. Introduction to ASD was delivered through both these methods, with information about autism being given to the students, but also explanatory material, with particular reference to behavioural, communication and sensory differences students with ASD may have.

It was considered novel and also reflective of the emerging evidence base that the intervention would include directive instruction too. The large evidence base of PMI was looked at for this aspect. Basic elements of prompting and reinforcement were included in the directive teaching (Wong et al., 2014). Directive instruction also emphasised allowing the students to develop confidence and understanding in communicating with students with ASD. Campbell and Barger (2014) speculate that directive guidance may alleviate fears and improve self-confidence in the peer group. The intervention was also designed to reflect contemporary conceptions of neurodiversity and autism, addressing attitudes and behaviours from this perspective. The evidence base for this type of educational perspective is limited, but it reflects contemporary practice and is inclusive of the views of the autism community (Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman, 2017; Kapp et al., 2013).

The three joint sessions gave students the opportunity to transfer the directive teaching into practice and have contact with students with ASD (Carter et al., 2014). It also allowed them understand conceptions of neurodiversity and diagnostic knowledge of autism as part of the individuals’ overall presentation. As an aim of the intervention
was also to promote inclusion, these joint sessions were vital. Support and communication with each other in the school setting was introduced at the start of each joint session and the students were actively encouraged to contribute ways they could work together or communicate with each other outside of the group. The idea of an ally, and how students could be allies was also reinforced at each session. The introductory session specifically focused on similarities and mutual connections between the students (Campbell et al., 2004). All the students received certificates for their participation in the project.

12.2.2.2 Delivery

As previously stated the project was delivered solely by the researcher, with support staff in attendance during the joint sessions. The researcher has a background and experience in delivering group-based programmes to adolescents both with and without ASD. Students were aware that the researcher worked in Trinity College Dublin and had expertise in the area. This was in keeping with Campbell (2004) findings that older students reacted more positively to an expert delivering information.

12.2.2.3 Outline of sessions

The first session’s focus was on explaining the purpose of the project, introducing the concept of an ally, giving an understanding of ASD as a diagnosis and from the perspective of a person with ASD. The information was descriptive and explanatory (Campbell et al., 2004). The diagnosis of ASD was presented according to DSM V criteria (APA, 2013). Quotations from books and well-known people with ASD were presented and discussed to give examples of first person perspectives of living with ASD. A definition of neurodiversity was also presented to assist with appreciating difference (Kapp et al., 2013). The concept of being an ally was reinforced by giving
dictionary definitions of “an ally” and “to ally”, i.e., an ally is a person who associates or cooperates with another or a supporter. To ally means to combine or unite resources with others for a shared benefit. The students were encouraged to consider these concepts in terms of students with ASD before the following week’s session.

The second session developed the idea of being an ally, by explaining the project would also involve joint sessions with students who had ASD in their school. The students were shown a video of a high school student called Dillan with ASD produced by Apple Inc. (Apple, 2016) to celebrate autism acceptance. Following this the students were encouraged to explore what their attitude would be to a student like Dillan in their own school, with a focus on exploring similarities and differences. This was further expanded on by then discussing how behaviour can demonstrate attitude. The session was concluded with information from research about secondary school students with ASD first hand reporting of the experience of secondary school (Saggers, 2015).

The third session was the first contact session with the students with ASD. It took place in the ASD classroom, with the intervention group being invited to join them. The environment was prepared beforehand in terms of seating and table arrangement. The students with ASD were also prepared for the intervention group. The session comprised of introducing the concept of “an ally” and “to ally” to the whole group and the expectation they could become allies. Ground rules were collaboratively established and recorded for the group sessions. The remainder of the session was dedicated to getting to know each other through structured activities which allowed the students to discover similarities and differences between them. All the activities were presented visually on handouts, and students were encouraged to contribute as much as possible. The session was concluded by presenting plans for the next two joint sessions.
The focus of the fourth session was to recap on the joint session from the perspective of communication skills and practical ways students can ally with each other. The students were asked to problem solve around how they could facilitate social interaction with students with ASD. The concept of prompting and reinforcing communications was introduced with examples and role play. Social interaction was defined. The purpose of visual supports was also introduced with examples of visual schedules shown to the students and discussed with reference to planned activities in the joint sessions. The students were given a hand-out on good communication skills which are ASD friendly and asked to consider these for the next joint session.

The fifth session was designed to consider sensory differences in ASD, but also how sensory processing can impact on school life for all students. The students completed a short sensory profile as an activity. There was also some simulated sensory activity to assist understanding how sensory differences can impact on behaviour. Descriptive and explanatory information was given about sensory differences and ASD. Finally, the students were challenged to consider how they could make spaces in the school more sensory friendly.

Session six was the second joint session with a focus on shared learning. It commenced with an ice breaker activity and recap on the concept of being an ally. The learning task was a cooperative small group construction task. Students were allocated their groups with each small group having one or two students with ASD and two or three students without ASD. The instructions were given visually and verbally, and students were given tips for successful completion. The activity was set up as a competition between groups with prizes for the outcome. On completion of the activity students were asked for feedback and ideas about what aspects of team work contributed to success or challenge.
The seventh session was used to debrief from the joint session, and allow the students further consider communication strategies, challenges to communication and strategies they could use to improve communication. Explanatory and descriptive information was presented in relation to reciprocal communication and strategies to encourage this with students with ASD. Scenarios were presented to identify ways students could encourage interaction with students who may have verbal communication or social skill difficulties. The students were also given the hand-out “Understanding The Spectrum – A Comic Strip Explanation” (Burgess, 2016). This provided them with a recap of the concepts relating to ASD and neurodiversity and emphasised the individuality of the ASD presentation.

The eighth session had a core focus on prompting and reinforcing interaction. The students were presented with descriptive information about the purpose of prompting and reinforcing interaction. Familiar techniques for prompting and reinforcing were demonstrated such as praise, high fives, physical encouragement, using a person’s name and body language. The hierarchy of prompting was presented to the students. Good practice in reinforcement was described. Students were asked to role play interactions identifying way of prompting, reinforcing and slowing down the interaction in order to encourage communication. The plan for the final joint session was presented. Students were encouraged to practice the strategies they had learnt about in the final session.

The ninth session was a joint social activity between the students with ASD and the intervention group. It was designed as a team treasure / scavenger hunt around the school. Maps and clues had been prepared prior to the session. Teams of three to four students were allocated. The rules were presented visually and verbally. Students were instructed to assign roles before the task, e.g., scribe, clue gatherer etc. When all
the teams arrived back at the ASD classroom prizes were given. The end of this session was used to award certificates of completion for Project ALLY to all the students. They also completed a reflective brain storm in groups about the project and completed the feedback questionnaires. See appendix C for more details.
Table 12.2 *Session by session outline of objectives for Project ALLY*

<table>
<thead>
<tr>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3 (Contact)</th>
<th>Session 4</th>
<th>Session 5</th>
<th>Session 6 (Contact)</th>
<th>Session 7</th>
<th>Session 8</th>
<th>Session 9 (Contact)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title</strong></td>
<td>Understanding Autism</td>
<td>Exploring attitudes and behaviours in school towards peers with Autism</td>
<td>Introductory session with ASD class</td>
<td>Being an ALLY</td>
<td>The sensory environment in school</td>
<td>Joint Learning Activity</td>
<td>ALLY to ALLY</td>
<td>Prompting and Reinforcing during interactions</td>
</tr>
<tr>
<td><strong>Objectives</strong></td>
<td>To complete baseline multiple choice test of knowledge</td>
<td>To explain purpose of project</td>
<td>To define an ALLY in the school setting</td>
<td>To give an understanding of Autism as a diagnosis</td>
<td>To understand Autism from the perspective of a person with autism</td>
<td>To define neurodiversity</td>
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<tr>
<td></td>
<td>• To complete baseline multiple choice test of knowledge</td>
<td>• To explain purpose of project</td>
<td>• To define an ALLY in the school setting</td>
<td>• To give an understanding of Autism as a diagnosis</td>
<td>• To understand Autism from the perspective of a person with autism</td>
<td>• To define neurodiversity</td>
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<tr>
<td></td>
<td>• Recap on session one</td>
<td>• Define and explore being an ALLY in relation to students with ASD</td>
<td>• Explore attitudes towards peers with autism, including understanding similarities and differences. Explore how behaviours can demonstrate attitude, using example of Dillan (video clip).</td>
<td>• Understand how students with autism experience</td>
<td>• Students to meet each other</td>
<td>• Debrief from joint session with feedback</td>
<td>• Recap on session three</td>
<td>• Recap on session four and joint learning session</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Establish ground rules for interaction sessions</td>
<td>• Compare similarities and differences</td>
<td>• Introduce plan for next two sessions</td>
<td>• Ice breaker activity</td>
<td>• Recap on session one and two</td>
<td>• To learn about sensory processing as it impacts on school life for all students.</td>
<td>• Explore reciprocity in communication and how to develop this</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Explore attitudes towards peers with autism</td>
<td></td>
<td></td>
<td>• Social small group activity</td>
<td>• Discuss and demonstrate practical ways students can ally with student with autism</td>
<td>• To identify sensory and behavioural differences common to autism and how they may impact on student in school.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Introduction to prompting and reinforcement during interactions.</td>
<td>• To experience sensory processing through experiential activity.</td>
<td>• To identify challenges to interaction with students who have verbal communication and or social skills difficulties</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Define social interaction</td>
<td>• To challenge students to analyse lunchtime from a sensory perspective</td>
<td>• To understand special interests as a means of interaction</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Practice good communicatio n skills, which are autism friendly</td>
<td>• To consider a way to make spaces more sensory /</td>
<td>• Learn how to provide structure to an activity</td>
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<tr>
<td></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Explore ways to model social interaction</td>
</tr>
</tbody>
</table>

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### Evidence Base

- **School-life (what the research tells us)**

- **Demonstrate how visuals can support interactions with students with autism.**

- **Autism friendly in school**

- **Practice prompting and reinforcing during an activity**

- **Role play ways of reinforcing interaction**

| Evidence Base | (Campbell & Barger, 2011; Gillespie-Lynch et al., 2015; Kapp et al., 2013) | (Ranson & Byrne, 2014; Sagger, 2015; Staniland & Byrne, 2013) | (Campbell et al., 2004; Carter et al., 2014) | (Carter et al., 2014; Ganz et al., 2012; Hart & Whalon, 2011; Hughes et al., 2013; Hughes et al., 2011) | (Tomchek & Dunn, 2007) | (Carter et al., 2014) | (Bambara et al., 2016; Carter, Asmus, et al., 2016; Carter et al., 2015; Carter et al., 2014; Chang & Locke, 2016; Humphrey & Symes, 2011; Koegel, Kim, Koegel, & Schwartzman, 2013; Koegel et al., 2012) | (Bambara et al., 2016; Carter, Asmus, et al., 2016; Carter et al., 2015; Carter et al., 2014; Chang & Locke, 2016; Harper, Symon, & Frea, 2008; Humphrey & Symes, 2011; Koegel et al., 2013; Koegel et al., 2012) | (Carter et al., 2014) |
12.2.3 Measures

12.2.3.1 Knowledge of Autism Scale
The Knowledge of Autism scale (KOA) is a 10-item True/False scale designed by Campbell and Barger (2011). Details pertaining to this measure are provided in Chapter 10.

12.2.3.2 Shared Activity Questionnaire
The Shared Activity Questionnaire (SAQ) is a 24-item questionnaire. Societal Attitude to Autism Scale. Details pertaining to this measure are provided in Chapter 10.

12.2.3.3 Societal Attitudes Towards Autism scale
The Societal Attitudes Towards Autism scale (SATA) is an autism specific scale designed to measure attitudes towards autism in the general population. Details pertaining to this measure are provided in Chapter 10.

12.2.3.4 Survey of Neurodiversity Conceptions
Aspects of a survey used to gain better insights into autism and neurodiversity concepts for parents, people with autism and their friends were used (Kapp et al., 2013). Details pertaining to this measure are provided in Chapter 10.

12.2.3.5 Multiple Choice Knowledge Test
An eight-item multiple choice knowledge test was designed for the purposes of this research to test pre- and post-knowledge based on the content of the intervention. The purpose of the knowledge test was to assess potential knowledge gain following the intervention. An edumetric analysis rather than a psychometric analysis was conducted on the test (Carver, 1974). When the primary focus of an assessment is measurement of individual gain before and after an educational programme, the assessment should be
evaluated in terms of its edumetric rather than its psychometric properties. This analysis examined: (1) item difficulty; (2) edumetric validity (i.e., the degree to which a measure captures gain in situations where it is expected), and (3) edumetric reliability (i.e., consistency of gain as reflected by the measure).

*Item difficulty.* The difficulty index of items on the knowledge test was assessed. The difficulty index is defined as the percentage of participants providing a correct response on a particular item. The optimal range is 20-80%, with a lower percentage indicating higher levels of difficulty (Dixon, 1994; Taib & Yusoff, 2014). At baseline, the difficulty index for items ranged from 0% to 87.5% ($M=29.6\%, SD=51.82\%$). At post-intervention testing, the difficulty index for items ranged from 50% to 100% ($M=82.14\%, SD=27.75\%)$.

*Edumetric validity.* Edumetric validity for the knowledge test was demonstrated; participants scored significantly higher on the test following completion of the intervention (Carver, 1974; Deniz & Alsaffar, 2013).

*Edumetric reliability.* Edumetric reliability can be evaluated by administering a measure on two occasions, under equivalent treatment conditions. The measure was administered on six separate occasions (i.e., twice to each of the three intervention groups) under similar conditions, and no between group differences were found.

### 12.2.3.6 Social Validity

The concept of social validity is taken from ABA research, with a view that ascertaining the acceptability of an intervention should form a key objective of its implementation (Wolf, 1978). This was done through a feedback measure from the student participants (intervention group and students with ASD) to elicit participating students views on the intervention. For the intervention group this entailed 23 statements addressing aspects
of the intervention such as time, levels of support, self-efficacy and learning. These questions were adapted from Asmus et al. (2017) and Carter, Asmus, et al. (2016) who examined peer network interventions. The student participants from the ASD classroom were given shorter versions, with similar statements, addressing their satisfaction with participating in the group sessions. The statements were answered on a three-point Likert scale, yes, maybe and no – face “emojis” were used to depict these as a visual aid for all students.

**12.2.4 Research Design**

The study was designed as an exploratory randomised control trial to evaluate the effects of Project ALLY on measures of knowledge of autism, attitude, intentional behaviours and concepts of neurodiversity. It also aimed to assess learning specific to the intervention content.

**12.2.5 Procedure**

Details of recruitment and school selection is identical to the processes reported in Chapter 10.

Scheduling of the data collection and project ALLY intervention sessions was negotiated with a volunteer member of staff in both schools. As it was transition year, this could be accommodated within the time table without too much disruption. These 72 students represented three class groupings, one class in first school and two in second. The study was carried out three times, once in the first school, and twice in the second school with 12 participants in the intervention condition and 12 participants in the control condition each time. A member of school staff randomly assigned the
students into the control and intervention conditions by splitting each class into two groups. Students were informed of their group allocation after the first data collection session. Twelve students were deemed the maximum number of students who could be facilitated within the ASD classrooms in both schools for the joint sessions. This also suited group work and interaction during the educational sessions.

12.2.5.1 Control Condition

The pre-intervention self-report measures (detailed in Chapter 10) were administered during a class session (40-45 minutes), one week prior to the commencement of the intervention. The control group participated in class as normal for the duration of the intervention which was six weeks. One week after the completion of the intervention the post-intervention self-report measures were administered during a class session.

12.2.5.2 Intervention Condition

The pre-intervention self-report measures were administered during a class session (40-45 minutes), one week prior to the commencement of the intervention. The intervention group participated in project ALLY which took place over six weeks. Project ALLY was devised and delivered by the researcher. It consisted of nine sessions, six of these were educational sessions which took place in a designated space within the school each week. Three of these sessions were joint with the ASD class and took place in the ASD classroom. These three sessions were evenly dispersed throughout the six weeks, one before sessions three and five and one at the end of the project. Where possible these sessions were double classes. Participants completed the multiple-choice knowledge pre-test at the beginning of session one, and post – test during the post-intervention
data collection session. Participants completed the social validity / feedback questionnaires during the final joint session. One week after the completion of the intervention the post-intervention self-report measures were administered during a class session.

12.2.5.3 Procedural fidelity

As the intervention was developed and delivered by the researcher, procedural fidelity was assured. Time tabling and student availability did impact the timing of sessions particularly in the first school. This meant that the intervention ran for longer than the six-week time frame. In the second school closer attention was paid to timetabling and organisation of the sessions prior to commencement.

12.3 Data Analysis

All data were stored in a password protected file and analysed using SPSS (version 24). Missing data, comparability of data and sample size were analysed.

12.3.1 Missing data and attrition

Analysis showed no out of range or non-random missing data (Little MCAR test) for the three measures (KOA, SATA and SAQ). There was very little missing data as students were given very clear instructions and asked to check all their answers. For the survey of neurodiversity concepts, there were a number of open ended questions which were left blank by students. A count of these is given in the descriptive statistics. Three students in the control groups did not complete the post-intervention measures. These three students’ data were excluded from comparative analysis at post-test but did not impact on comparability of data.
12.3.2 Sample size

An estimated sample size was calculated using the statistical power package (G*Power). Comparable studies were limited, with effect size reporting minimal. The estimated sample size on a priori alpha levels of .05 for a medium effect size was 176 and for a large effect was 70, for independent t-test analysis.

12.3.3 Comparability

Self-report measures and predictor variable distribution was checked for comparability at pre-test and post-test. As data from the self-report measures were found to be not normally distributed and based on Likert scales, the non-parametric Mann Whitney U tests were used to compare mean scores (Jamieson, 2004). These failed to reject the null hypothesis indicating there the two groups were comparable on the self-report measures. Chi-square analysis was not significant for the predictor variables of gender and previous experience of autism across the control and intervention groups, demonstrating they were comparable for these variables also.

Table 12.3 Characteristics of participants by group

<table>
<thead>
<tr>
<th></th>
<th>Control n</th>
<th>Intervention n</th>
<th>( x^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>21</td>
<td>19</td>
<td>.635</td>
</tr>
<tr>
<td>female</td>
<td>15</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Experience of ASD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>17</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>19</td>
<td>17</td>
<td>.637</td>
</tr>
</tbody>
</table>
12.3.4 Statistical analysis

To analyse differences between the two groups on the three self-report measures, change scores were calculated. Tests of normality for change scores revealed the data were positively skewed. Using the Shapiro-Wilk test, the scores were not normally distributed for KOA, SATA and SAQ - A. Non-parametric tests were used for analysis of these scores. An alpha level of .05 was used for all tests. T-test and Mann-Whitney U tests were used to compare change scores across the groups. Cohen’s d was used to calculate effect sizes.

Secondary analysis was conducted using multiple linear regression across groups to predict changes in knowledge, attitudes and intentional behaviours. The three predictor variables were intervention/control group, gender and prior experience of autism.

For the survey of neurodiversity concepts, categorical data were analysed using chi-square analysis. For the qualitative coded data, where possible chi-square analysis was also conducted, or descriptive pre-post information presented.

The multiple-choice test of knowledge was completed by the intervention group only. A matched pair t-test were used to analyse increases in knowledge pre- and post-intervention and effect size calculated.

The social validity/feedback questionnaire is reported descriptively for the transition year students and students from ASD classes.
12.4 Results

12.4.1 Change scores and effect on self-report measures

Table 12.4 indicates the mean change, and effect size for intervention and control group on the SAQ, KOA and SATA. Calculations of change scores indicated that means for the intervention group were in the predicted direction. Table 12.5 and 12.6 show the post – intervention minimum, maximum and mean score for the KOA, SATA and SAQ which demonstrates the positive direction of the scores changes.

Table 12.4 Change scores and effect size

<table>
<thead>
<tr>
<th>Measure</th>
<th>Group</th>
<th>n</th>
<th>Mean change</th>
<th>SD</th>
<th>Effect size (Cohen’s d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General social (SAQ)</td>
<td>Intervention</td>
<td>36</td>
<td>1.72</td>
<td>2.43</td>
<td>1.07 (large)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>33</td>
<td>-.84</td>
<td>2.43</td>
<td></td>
</tr>
<tr>
<td>Active recreation (SAQ)</td>
<td>Intervention</td>
<td>36</td>
<td>2.13</td>
<td>3.54</td>
<td>.56 (moderate)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>33</td>
<td>.18</td>
<td>3.59</td>
<td></td>
</tr>
<tr>
<td>Academic (SAQ)</td>
<td>Intervention</td>
<td>36</td>
<td>2.47</td>
<td>3.75</td>
<td>.93 (large)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>33</td>
<td>-.75</td>
<td>3.26</td>
<td></td>
</tr>
<tr>
<td>KOA</td>
<td>Intervention</td>
<td>36</td>
<td>.63</td>
<td>1.24</td>
<td>.39 (small)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>33</td>
<td>.06</td>
<td>1.63</td>
<td></td>
</tr>
<tr>
<td>SATA</td>
<td>Intervention</td>
<td>36</td>
<td>3.94</td>
<td>5.68</td>
<td>.59 (moderate)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>33</td>
<td>1.09</td>
<td>3.91</td>
<td></td>
</tr>
<tr>
<td>SAQ</td>
<td>Intervention</td>
<td>36</td>
<td>6.33</td>
<td>7.79</td>
<td>.79 (moderate)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>33</td>
<td>.63</td>
<td>6.80</td>
<td></td>
</tr>
</tbody>
</table>
Independent Sample Mann Whitney U test showed that the distribution does not differ significantly across the two groups for the KOA, \( U = 469, \ Z = -1.557, \ p = 0.120 \).

For all other self-report measures a significant difference was found between the groups. An Independent Sample Mann Whitney U test shows that the distribution does differ significantly across categories of control and intervention for the SATA, \( U = 421, \ Z = -2.094, \ p = 0.036 \) and SAQ-A, \( U = 362.50, \ Z = -2.810, \ p = 0.05 \). An Independent Sample t-test shows that the distribution does differ significantly across categories of control and intervention for SAQ-GS, \( t(67) = 4.379, \ p < 0.001 \); SAQ-AR, \( t(67) = 2.276, \ p = 0.026 \) and total SAQ \( t(67) = 4.00, \ p < 0.001 \).

Table 12.5 Post-intervention KOA score by group

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Min.</th>
<th>Max.</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>POSTKOA</td>
<td>33</td>
<td>4.00</td>
<td>10.00</td>
</tr>
<tr>
<td>Intervention</td>
<td>POSTKOA</td>
<td>36</td>
<td>8.00</td>
<td>10.00</td>
</tr>
</tbody>
</table>

Table 12.6 Post-intervention SATA and SAQ scores by group

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Min.</th>
<th>Max.</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>control</td>
<td>SATA*</td>
<td>33</td>
<td>32.00</td>
<td>62.00</td>
</tr>
<tr>
<td></td>
<td>SAQ – GS**</td>
<td>33</td>
<td>10.00</td>
<td>24.00</td>
</tr>
<tr>
<td></td>
<td>SAQ – A**</td>
<td>33</td>
<td>10.00</td>
<td>24.00</td>
</tr>
<tr>
<td></td>
<td>SAQ – R**</td>
<td>33</td>
<td>8.00</td>
<td>23.00</td>
</tr>
<tr>
<td></td>
<td>SAQ **</td>
<td>33</td>
<td>30.00</td>
<td>71.00</td>
</tr>
<tr>
<td></td>
<td>Total***</td>
<td>33</td>
<td>30.00</td>
<td>71.00</td>
</tr>
<tr>
<td>Intervention</td>
<td>SATA*</td>
<td>36</td>
<td>44.00</td>
<td>61.00</td>
</tr>
<tr>
<td></td>
<td>SAQ – GS**</td>
<td>36</td>
<td>15.00</td>
<td>24.00</td>
</tr>
<tr>
<td></td>
<td>SAQ – A**</td>
<td>36</td>
<td>14.00</td>
<td>24.00</td>
</tr>
<tr>
<td></td>
<td>SAQ – R**</td>
<td>36</td>
<td>14.00</td>
<td>24.00</td>
</tr>
<tr>
<td></td>
<td>SAQ **</td>
<td>36</td>
<td>47.00</td>
<td>72.00</td>
</tr>
<tr>
<td></td>
<td>Total***</td>
<td>36</td>
<td>47.00</td>
<td>72.00</td>
</tr>
</tbody>
</table>

range *16-64 **8-24 ***24-72
12.4.2 Covariates – Experience of autism and Gender

For the covariate of experience of autism, no statistically significant difference was found for SAQ or SATA.

An Independent Sample Mann Whitney U test shows that the distribution does differ significantly for experience of autism for KOA scores, $U=414.50$, $Z=-2.236$, $p=0.025$. Those with no experience of autism had higher change scores on KOA.

For the covariate of gender, no statistically significant difference was found for KOA, SAQ or SATA.

12.4.3 Secondary analysis

A series of multiple linear regression analyses were conducted to investigate if gender, previous experience of autism or intervention group were predictive of the knowledge, attitude and behavioural intention outcomes.

For the three factors being predictive of knowledge of autism (KOA), the total variance explained by the model was not significant $F(3) = 2.49$ $p=0.68$. Only previous experience of autism was statistically significant as an individual predictor of KOA ($beta = .229$, $p<.05$).

For the three factors being predictive of attitude (SATA), the total variance explained by the model was not quite significant $F(3) = 1.879$ $p=.142$. Only participating in the intervention was statistically significant as an individual predictor of SATA ($beta = .284$, $p<.05$).

For the three factors being predictive of general social behavioural intentions (GS-SAQ) the total variance explained by the model was 26.2%, $F(3) = 7.688$ $p<.001$. Only participating in the intervention was statistically significant as an individual predictor of GS-SAQ ($beta = .484$, $p<.001$).
For the three factors being predictive of academic behavioural intentions (A-SAQ) the total variance explained by the model was 12.7%, F(3) = 3.139  p<.05. Only participating in the intervention was statistically significant as an individual predictor of A-SAQ (beta = .356 p<.05).

For the three factors being predictive of active recreation behavioural intentions (AR-SAQ) the total variance explained by the model was not significant, F(3) = 1.874 p=.143. Only participating in the intervention was statistically significant as an individual predictor of AR-SAQ (beta = .274 p<.05).

For the three factors being predictive of all behavioural intentions (SAQ) the total variance explained by the model was 21%, F(3) = 5.75 p<.01. Only participating in the intervention was statistically significant as an individual predictor of SAQ (beta = .452 p<.001).

12.4.4 Neurodiversity survey
Table 12.7 presents the descriptive data for awareness of the term neurodiversity. Table 12.8 presents descriptive data for answers to questions relating to attitude to concepts linked to parenting and neurodiversity.

Table 12.7 Awareness of Neurodiversity pre- and post-intervention

<table>
<thead>
<tr>
<th>Are you aware of the term Neurodiversity? (N)</th>
<th>No percent (n)</th>
<th>Yes percent (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control pre (36)</td>
<td>97.0 (35)</td>
<td>3.0 (1)</td>
</tr>
<tr>
<td>Intervention Pre (36)</td>
<td>92.0 (33)</td>
<td>8.0 (3)</td>
</tr>
<tr>
<td>Control Post (33)</td>
<td>94.0 (31)</td>
<td>6.0 (2)</td>
</tr>
<tr>
<td>Intervention Post (36)</td>
<td>2.8 (1)</td>
<td>97.2 (35)</td>
</tr>
</tbody>
</table>
Table 12.8 *Attitude to neurodiversity questions pre- and post-intervention*

<table>
<thead>
<tr>
<th>Attitude to Neurodiversity</th>
<th>Agree Pre-intervention percent (N=72)</th>
<th>Agree Post-intervention percent (N=69)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Parents should seek a cure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>69.4 (25)</td>
<td>66.7 (22)</td>
</tr>
<tr>
<td>Intervention</td>
<td>52.7 (19)</td>
<td>30.5 (11)</td>
</tr>
<tr>
<td>2. Teach child to develop skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>100 (36)</td>
<td>93.9 (31)</td>
</tr>
<tr>
<td>Intervention</td>
<td>97.0 (35)</td>
<td>100.0 (36)</td>
</tr>
<tr>
<td>3. Teach child to appear more like a typical person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>72.2 (26)</td>
<td>75.76 (25)</td>
</tr>
<tr>
<td>Intervention</td>
<td>50.0 (18)</td>
<td>47.2 (17)</td>
</tr>
<tr>
<td>4. Understand autism as part of their identity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>88.9 (32)</td>
<td>90.1 (30)</td>
</tr>
<tr>
<td>Intervention</td>
<td>97.0 (35)</td>
<td>100 (36)</td>
</tr>
<tr>
<td>5. Try to learn why their child is on the autism spectrum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>88.9 (32)</td>
<td>93.9 (31)</td>
</tr>
<tr>
<td>Intervention</td>
<td>83.3 (30)</td>
<td>83.3 (30)</td>
</tr>
<tr>
<td>6. Learn to speak their child’s language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>88.9 (32)</td>
<td>93.9 (31)</td>
</tr>
<tr>
<td>Intervention</td>
<td>100 (36)</td>
<td>100.0 (36)</td>
</tr>
</tbody>
</table>
Chi-square analysis or Fischer exact test (when sample less than 5) showed no significant difference between the two groups at pre-test, indicating they were comparable.

At post-test there was no significant difference between the two groups on questions two, four, five and six.

Chi-square analysis found a relationship between groups and whether parents should seek a cure for their child, $x^2 (1, N = 69) = 4.327, p < .05$. Participants in the intervention group were less likely to agree that parents should seek a cure for their child.

Chi-square analysis found a relationship between groups and whether parents should teach a child to appear more like a typical person, $x^2 (1, N = 69) = 5.886, p < .05$. Participants in the intervention group were less likely to agree that parents should teach their child to appear more like a typical person.

12.4.5 Qualitative findings

12.4.5.1 Awareness of the term neurodiversity

Pre-intervention, 5.6% (n=2) of the students in the control group and 5.6% (n=2) in the intervention group reported being aware of the term neurodiversity. Post Intervention, 3% (n=1) of the students in the control group and 100% (n=36) reported being aware of the term neurodiversity. Some 16% (6) students in the control group and 25% (9) in the intervention groups gave definitions of neurodiversity which were coded as relating to brain differences. Post intervention 18% (6) students in the control group and 69% (25) students in the intervention group gave definitions coded as relating to brain difference. The intervention group were noted to also provide more specific answers referencing ASD.
12.4.5.2 Emotions associated with having autism

The control group selected 56 emotions pre-intervention and 60 emotions post-intervention. The Intervention group selected 75 emotions pre-intervention and 98 post-intervention.

The control group indicated 16% pre and 13% post of their selected emotions as positive (happy, proud, content and excited). The Intervention group indicated 14% pre and 28% post of their selected emotions as positive.

The control group indicated 77% pre and 66% post of their selected emotions as negative (sad, overwhelmed, frustrated, angry, ashamed and confused). The intervention group indicated 70% pre and 61% post of their selected emotions as negative (sad, overwhelmed, frustrated, angry, ashamed and confused).

12.4.5.3 Causes of Autism

Students answered an open-ended question as to what they considered the causes of Autism. Table 12.9 describes the coded responses.

Table 12.9 Coded Responses for Causes of Autism

<table>
<thead>
<tr>
<th>*Causes of Autism Percent</th>
<th>Control Pre (n=36)</th>
<th>Intervention Pre (n=36)</th>
<th>Control Post (n=33)</th>
<th>Intervention Post (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological</td>
<td>25 (9)</td>
<td>28 (10)</td>
<td>15 (5)</td>
<td>78 (28)</td>
</tr>
<tr>
<td>Social Environment</td>
<td>3 (1)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Physical environment</td>
<td>0</td>
<td>6 (2)</td>
<td>3 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Multiple causes</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3 (1)**</td>
</tr>
<tr>
<td>Other</td>
<td>6 (2)</td>
<td>25 (9)</td>
<td>3 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Validity rejection</td>
<td>3 (1)</td>
<td>3 (1)</td>
<td>3 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Don’t know</td>
<td>36 (13)</td>
<td>28 (10)</td>
<td>39 (13)</td>
<td>6 (2)</td>
</tr>
<tr>
<td>No Answer</td>
<td>28 (10)</td>
<td>11 (4)</td>
<td>36 (12)</td>
<td>14 (5)</td>
</tr>
</tbody>
</table>

*codes are presented in chapter 10 **biological and developmental
Chi-square analysis found a difference between the control and intervention groups post intervention and attributing a biological cause to autism, $x^2 (1, N = 69) = 27.062$, $p < .001$. Participants in the intervention group were more likely to attribute a biological cause to autism than the control group.

12.4.6 Multiple-choice test of knowledge

The 36 participants in the intervention group completed a pre and post intervention eight item multiple choice test based on the content of the sessions. The mean score pre-intervention was 2.38 (1.77) and post 7.13 (1.96), with a mean increase in score of 4.75 (1.51). A paired sample t-test shows that the distribution does differ significantly across pre- and post-intervention $t (35) = 18.76$, $p = <0.001$. Cohen’s $d = 3.48$ which is a very large effect size.

12.4.7 Social Validity

Students in the intervention group and in the ASD class group completed feedback questionnaires. Findings are presented in table 12.10.
<table>
<thead>
<tr>
<th>Question</th>
<th>N=36</th>
</tr>
</thead>
<tbody>
<tr>
<td>Students in the “autism class name” benefited socially from the project?</td>
<td></td>
</tr>
<tr>
<td>I benefited socially from the project?</td>
<td></td>
</tr>
<tr>
<td>Overall, I enjoyed participating in this project?</td>
<td></td>
</tr>
<tr>
<td>The amount of time required was reasonable?</td>
<td></td>
</tr>
<tr>
<td>I would need ongoing support to keep up what I learnt?</td>
<td></td>
</tr>
<tr>
<td>Students in “autism class name” have more friends / allies because of this project?</td>
<td></td>
</tr>
<tr>
<td>I could use things I learnt in this project with other people?</td>
<td></td>
</tr>
<tr>
<td>I feel I was effective as a participant?</td>
<td></td>
</tr>
<tr>
<td>I took part with enthusiasm?</td>
<td></td>
</tr>
<tr>
<td>The project was a good way to include the students from “autism class name”?</td>
<td></td>
</tr>
<tr>
<td>I felt confident during the project?</td>
<td></td>
</tr>
<tr>
<td>I felt I had enough help and support to be part of this project?</td>
<td></td>
</tr>
<tr>
<td>The project was too much work for me?</td>
<td></td>
</tr>
<tr>
<td>I feel I was effective in this project?</td>
<td></td>
</tr>
<tr>
<td>The information sessions were useful?</td>
<td></td>
</tr>
<tr>
<td>Other 4th year students should do this?</td>
<td></td>
</tr>
<tr>
<td>I would do a project like this again?</td>
<td></td>
</tr>
<tr>
<td>I understand why 4th year students are better for this project than teachers / adults?</td>
<td></td>
</tr>
<tr>
<td>I would consider the students in “autism class name” are my allies / friends?</td>
<td></td>
</tr>
<tr>
<td>I would recommend this project to others?</td>
<td></td>
</tr>
<tr>
<td>My views about students with autism have changed?</td>
<td></td>
</tr>
<tr>
<td>My views about people who are neurodiverse have changed?</td>
<td></td>
</tr>
<tr>
<td>*additional comment: “my views were already positive”</td>
<td></td>
</tr>
</tbody>
</table>

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Table 12.11 *Students with ASD feedback*

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes (percent) n</th>
<th>Maybe (percent) n</th>
<th>No (percent) n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you like going to school?</td>
<td>54 (7)</td>
<td>46 (6)</td>
<td>0</td>
</tr>
<tr>
<td>Do you have friends at school?</td>
<td>92 (12)</td>
<td>0</td>
<td>8 (1)</td>
</tr>
<tr>
<td>Do you like this Project ALLY class?</td>
<td>77 (10)</td>
<td>23 (3)</td>
<td>0</td>
</tr>
<tr>
<td>Did you learn new things in this class?</td>
<td>77 (10)</td>
<td>8 (1)</td>
<td>15 (2)</td>
</tr>
<tr>
<td>Did you like working with the 4th years in this class?</td>
<td>92 (12)</td>
<td>8 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Did working with the 4th years help you learn new things?</td>
<td>61 (8)</td>
<td>31 (4)</td>
<td>8 (1)</td>
</tr>
<tr>
<td>Did you make new friends?</td>
<td>69 (9)</td>
<td>8 (1)</td>
<td>23 (3)</td>
</tr>
<tr>
<td>Would you like to keep working with the 4th years?</td>
<td>77 (10)</td>
<td>15 (2)</td>
<td>8 (1)</td>
</tr>
</tbody>
</table>

*One student missed the feedback session

12.5 Discussion

The primary aim of this study was to assess the efficacy of a specifically designed autism acceptance intervention, for transition year students in two co-educational schools in Ireland.

It involved the development of a nine-session intervention, named Project ALLY which included three group sessions with students who attended the schools ASD classes. Project ALLY was developed using literature and best practice guidelines (Campbell & Barger, 2014; Campbell et al., 2004; Carter et al., 2014).
12.5.1 Results of the intervention as applied to previous research

12.5.1.1 Knowledge

The students in the intervention project ALLY group showed a small change in their scores on the Knowledge of Autism (KOA) scale in this study. Although this initially seems surprising as they had participated in an intervention designed to teach them about autism, on analysis this result can be considered from a number of perspectives. Firstly, the scale itself may not have been adequate to pick up knowledge change. Secondly, the students showed a high level of autism knowledge from the outset and thirdly, the emphasis of the intervention on neurodiversity and understanding autism from the perspective of the student with autism may not have been reflected in the measure. As already alluded to there are noted methodological concerns in relation to ASD knowledge measures (Harrison et al., 2016). The KOA was developed specifically for middle school age children, and despite poor internal consistency it was deemed the only established measure (Campbell & Barger, 2011). The students in this study were slightly older than Campbell’s’ sample. The students in this study demonstrated quite high knowledge of ASD based on this measure, both before and after the intervention. These high scores meant that any changes were small. The students’ understanding of the causes of autism did change, with a greater number giving accurate descriptive answers as to what they considered the cause after the intervention. It is also observed in the data that the minimum post intervention score was 8 out of 10 as opposed to the 4 out of 10 in the control group. Prior to intervention the minimum score was 5 out of 10 in both groups. Based on the KOA all students who participated in the ALLY program scored between 80 and 100% on the KOA. The KOA measure is designed to look
specifically at students’ knowledge of the cause, course, symptoms, and communicability of autism. It was also originally designed to complement an information video about autism in a study conducted in 2005. Project ALLY’s emphasis on autism knowledge gave a greater emphasis on understanding ASD from the perspective of the individual and made use of first person accounts as well as addressing core symptoms and causes. Gillespie-Lynch et al. (2015) point out that knowledge of autism is ever evolving, and what constitutes acceptable levels of knowledge in 2005 may have shifted. Project ALLY reflected this, but potentially the KOA does not. This would echo the message of Harrison, Bradshaw, Naqvi, Paff, and Campbell (2017) for a need to develop more current and psychometrically sound knowledge measures. Knowledge of autism was positively associated with experience of autism across the group, both pre and post intervention. This finding is similar to other studies, particularly Campbell’s body of work which demonstrated experience of autism being a key factor in knowledge (Campbell & Barger, 2011). This study also demonstrated those without prior experience of autism in the project ALLY group made the most gains in knowledge.

In relation to knowledge specific to the intervention, and eight question multiple choice test was devised for the purposes of the intervention. It demonstrated sound edumetric properties. The students showed a large difference in knowledge post intervention, as would be expected. This demonstrated that they had learn specific information during the intervention.

12.5.1.2 Attitude and Intentional Behaviour

Project ALLY was designed to specifically address attitude and intentional behaviour, based on the view that students who have more positive attitudes about peers with ASD are more likely to behave in a pro-social manner towards them (Tonnsen & Hahn,
The students in the Project ALLY group demonstrated gains in attitude and intentional behaviour as measured by the SATA and the SAQ (Campbell, 2008; Flood et al., 2013; Morgan et al., 1996). There was a large effect for gains in structured activity and academic aspects of behavioural intention. There was a moderate effect for gains in recreational activity as measured by the SAQ and for the SATA. Being a member of the project ALLY group was predictive of these gains on regression analysis. The intervention combined descriptive, explanatory, directive information and contact with peers. This combination of intervention factors has not been reported in the literature and is considered the most likely reason for the strong findings in terms of attitude and intentional behaviour. Previous research has not found any or very small effects for intentional behaviour change post intervention (Ranson & Byrne, 2014; Staniland & Byrne, 2013). On analysis it appears that the differential factor in this intervention is the contact sessions, which were preceded with directive information on communication strategies for the participating students. Very brief video-based information sessions have shown no change in attitude (Campbell, 2007; Campbell et al., 2004; Swaim & Morgan, 2001). Longer intervention with students of a similar age to this study also showed minimal to no effects on intentional behaviour using the SAQ (Ranson & Byrne, 2014; Staniland & Byrne, 2013). These longer studies both analysed a similar intervention which comprised of descriptive, explanatory and directive information specific to High Functioning Autism (HFA). However, these interventions did not include a peer experience, the contact aspect of them was a talk by someone with HFA. Potentially the differential factor in this study was the actual peer experiences. The students were facilitated in shared activities and were given directive instruction on communication strategies, basic prompting and reinforcement of communication. All the students were also introduced to the concept of being an ally,
i.e., supporting and co-operating with each other and uniting resources for a shared benefit. Although still unknown why exactly directive strategies in particular may be effective, it is suggested that they give students a sense of confidence and self-efficacy when entering into peer contact groups (Campbell & Barger, 2014).

The large effects for general social and academic domains of intentional behaviour is also of interest. These two domains are representative of activities within the school, whilst the third domain of active recreation which showed a medium effect represents out of school activity. The activities participated in the joint session reflected shared learning and shared social activities and were potentially influencing factors in students changing attitudes.

12.5.1.3 Gender, age and prior experience of autism

Gender, age and prior experience of autism are the most researched covariates in understanding attitude. This study was carried out in mixed schools, with students aged between 15 and 16 years, neither this context nor age group has been presented in autism awareness intervention studies before, so comparisons are challenging. Studies of attitudes have demonstrated that attitudes appear to improve with age. College students demonstrate more positive findings than those of younger primary school aged children (Campbell, 2008; Gillespie-Lynch et al., 2015; Morgan et al., 1996; Nevill & White, 2011). Prior to intervention the students reported high to neutral attitudes and behavioural intentions, the Project ALLY group demonstrated that participation in an intervention further improved this. It was also observed in the data that variance in the spread of scores reduced in the intervention group. The students in this study demonstrate attitudes more comparable with emerging adulthood i.e., from 18 years, than the studies of younger primary school aged children. Emerging adulthood is
characterised by increased acceptance, tolerance and an openness to diversity (Arnett, 2000).

Gender did not impact on any of the results, other than females showed higher general social intentional behaviours pre-intervention. Findings from other studies have been mixed (Gardiner & Iarocci, 2014). Younger girls are generally thought to have more empathetic attitudes, but this has not held true in studies with older participants (Nevill & White, 2011). The co-educational contexts of this study may well have moderated the effect of gender. All the peers with ASD were male, as were the hypothetical peers presented in the SAQ. Fleva (2014) suggests that this may influence males more positively.

Prior experience of autism was not found to influence attitude or intentional behaviour either before or after intervention. As indicated students with prior experience had better pre-intervention knowledge, however this was not reflected in their attitudes. Gardiner and Iarocci (2014) point out that the quality of this experience may be key to its influence on attitude. As the quality or quantity of students’ prior experience was not established pre-intervention, it is not possible to analyse this. Importantly all the students in project ALLY had a positive experience (as reported through feedback post-intervention) with their peers with autism and demonstrated improved attitude. Gardiner and Iarocci (2014) study of university students’ acceptance of ASD and intention to volunteer with students with ASD demonstrated a positive attitude towards students with ASD is likely to predict positive changes in behaviour. Similarly, Campbell (2004) purports that behavioural intentions are one of the best predictors of actual behaviour.
12.5.1.4 Concepts of Neurodiversity

As the concept of neurodiversity and a biopsychosocial perspective were weaved through the Project ALLY intervention, these concepts were also measured. Pre-intervention 5.6% of the control group and 5.6% of the intervention group reported to having heard of the term neurodiversity. Despite this 16% of the control group and 25% of the intervention group were able to state that the term was associated with something relating to brain difference. Post Project ALLY all the intervention group reported to have heard of the term neurodiversity, 69 percent of them also gave an accurate definition. The other students did not give an inaccurate response but left this section on the questionnaire blank. These results demonstrated that the students had learnt about neurodiversity and had conceptualised the term. Understanding autism as a form of diversity rather than solely as a medical disorder has been associated with lower stigma (Gillespie-Lynch et al., 2017; Kapp et al., 2013). This is an important factor in autism acceptance and will potentially influence these students in terms of their interaction and attitude towards individuals with autism outside of the school setting also. Autism acceptance is beginning to be acknowledged as a protective factor in mental health of adults with autism (Cage et al., 2017). In terms of students’ attitudes towards parenting and autism, these questions were designed to examine the students’ attitudes to concepts closely related to neurodiversity. Although these questions were adapted from a study designed for adults (Kapp et al., 2013). Concepts related to neurodiversity were explained throughout Project ALLY, however there was no input relating to views on parenting or similar. Prior to the intervention prior experience of autism influenced students opinions on seeking a cure, with those who had experience were less likely to agree parents should seek a cure. Post intervention the control groups attitudes did no change. The participants from project ALLY became more likely to disagree with the
statement that parents should seek a cure, and to disagree with the statement that parents should teach their child to be more like a typical child. Recent online research with adults, demonstrated a shift in thinking away from a medical view or model towards a more nuanced view, which reflects neurodiversity but also acknowledges the need for supports which meet the needs of those with autism (Gillespie-Lynch et al., 2015; Gillespie-Lynch et al., 2017; Kapp et al., 2013). Those who adopted these views were less likely to have stigmatised views of people with autism.

In terms of associated emotions with autism, the project ALLY group indicated more positive emotions post intervention (from 14 to 28 percent of selected emotions). Similarly, Kapp et al. (2013) found that adults who were aware of neurodiversity selected more positive emotions about autism than those who were not aware of neurodiversity. However, the selection of negative emotions remained larger in both groups both pre and post intervention. Kapp et al. (2013) argue that this finding reflects a nuanced view of autism which recognises the strengths of autism but does not necessarily negate understanding the difficulties associated with autism.

Project ALLY considered how interpersonal skills of those without autism and societal factors may exacerbate the social challenges for students with autism. If students understand the social challenges for those with autism to be mutual, there is a better chance of impacting on the challenge (Gillespie-Lynch et al., 2017). But before they can do this they need to understand autism. Being made aware of autism has been shown to improve attitudes towards those with autism (Brosnan & Mills, 2016).
12.5.1.5 Social Validity

The feedback from students in the intervention group and the ASD class was very positive. Examining factors relating to continuation of the project, a large majority from both groups agreed they would like to continue or do it again. The intervention group were also strong in their suggestion that other 4th years should get the opportunity to be part of the project. Of note 47% of students felt they might require on-going support to continue with the program, and 36% answered ‘maybe’ to whether they felt confident during the project. It is potentially an under researched aspect in relation to peer relationships between students with ASD in the school setting that the social confidence of the peer without autism may also be a factor in reduced social interactions. In studies of PMI with adolescents, social validity is also generally reported with high rates of satisfaction (Asmus et al., 2017; Hughes et al., 2013; Koegel et al., 2013). Peers without ASD report to have enjoyed and benefited from the experience and rates of social interaction have been observed to increase (Hughes et al., 2011). The students in this study also reported that their views on ASD had changed, to what extent this was through contact and to what extent it was through educational intervention is unknown. The students with ASD were also generally very positive about the group, believing it was useful and that for many they had made new friends and would like to continue with the programme.

Other aspects to social validity which were not assessed include teacher and school personnel feedback and the feasibility of implementing the programme in schools. Anecdotally the feedback from teachers and staff was very positive with many commenting on observed increases in social reciprocity between students with ASD and 4th years on the corridors and at break times. The programme itself is also quite feasible to run in schools but does require timetabling and small groups. Transition year appears
to be the ideal time to implement this type of program as there is flexibility in the timetable and an expectation the students will participate in civic and social activity (Ireland, 1993).

Carter, Asmus, et al. (2016) note that despite strong endorsement for programs which improve peer social supports and connections and the relatively low cost and effort of implementing them, they often remain elusive and outside of research partnerships or endeavours.

12.5.2 Conclusion, Future Directions and Limitations
This study provides a new dimension to understanding the impact of autism acceptance programs for secondary school students. As an exploratory randomised control trial, it significantly improves the evidence base for the efficacy of structured educational programmes designed to improve knowledge, attitude and intentional behaviours towards peers with autism. The two most comparable studies conducted in Australian secondary schools had weaker findings in relation to behavioural intentions (Ranson & Byrne, 2014; Staniland & Byrne, 2013). These interventions did not include contact with peers with ASD, which may be the differentiating factor between these two studies and the intervention presented in this research. The inclusion of a structured contact element within an educational programme allowed the students to develop understanding of ASD within their own school community as well as appreciating ASD within society also. The directive strategies may have enabled the students to feel more confident in their interactions as suggested by Campbell and Barger (2014). This is an area which requires more research and a key recommendation of this study is to address how future autism acceptance programmes can incorporate more learning of these types
of strategies, which are often included as part of PMI and peer network interventions (Carter, Gustafson, et al., 2016; Hughes et al., 2013).

The students in this intervention also demonstrated increased knowledge of concepts relating to neurodiversity, and a slight shift in attitude away from medical model conceptions of curing ASD, to a recognition of the individual as neurodiverse. This is a contemporary view of ASD, which reflects the influence of people with ASD emerging voice within research and intervention fields (Baines, 2012). Research with older college students and adults has reflected this view, and this research demonstrates that adolescents can also take on these concepts (Gillespie-Lynch et al., 2015; Gillespie-Lynch et al., 2017; Kapp et al., 2013). It is recognised that this view of ASD can create more inclusive environments and potentially has protective factors against mental health difficulties for those with ASD (Cage et al., 2016; Cage et al., 2017). It is therefore recommended that this branch of autism acceptance programmes in schools be further developed and researched with particular emphasis on the impact it can have on inclusive behaviours and prevention a risk factors associated with depression and anxiety in students with ASD.

The positive feedback retrieved through the use of a social validity measure was also an important aspect to evaluating the intervention. Although ABA and particularly PMI have reported on social validity, there was little evidence of it in any other studies of autism acceptance programmes in schools (e.g., Staniland & Byrne, 2013). The positive feedback from students with and without ASD indicated that they would welcome the continuation and potentially progression of this type of intervention. The reported social gains by both groups indicate that in light of many negative findings relating to social experiences of students with ASD in secondary schools, and
intervention of this type is worth pursuing and developing (Humphrey & Hebron, 2015; Humphrey & Symes, 2010a, 2011).

Limitations to this study include a lack of follow up data, small sample size and the lack of any observational or implicit measures. As this was an initial exploratory study to test out the efficacy of an autism acceptance intervention in secondary schools, follow up data were not collected, and the sample size was only large enough to detect large effect. However, based on the positive findings it is recommended that the intervention be examined with a larger sample size and that follow up and maintenance be considered as part of this further study.

All of the measures utilised were self-report, with some psychometric issues relating to the KOA (Campbell & Barger, 2011). Self-report measures run the risk of socially desirable responses and without any other observational or implicit measures it is difficult to ascertain if this was a factor in students reporting of attitude and intentional behaviour. However, the use of a control condition regulates for this. Observational data has provided rich findings into the development and maintenance of social network intervention and would be a useful addition to this study (Asmus et al., 2017). Anecdotal reports from teaching staff and SNAs alluded to increased social contacts between the students outside of the classroom but there was no method for gathering this information.

The focus of the contact element in project ALLY was specific to students who attended ASD classes. The intervention did not differentiate between levels of support or severity of ASD core deficits. This may have led to a lack of awareness around less severe presentations of ASD within the school setting. It is recommended materials and resources be improved to reflect the spectrum of ASD in the intervention. Future studies utilising the project ALLY material will also need fidelity checks and consistency of
delivery of the material across multiple setting and potentially multiple facilitators. It is unknown if the delivery of the programme by the researcher, who has experience and expertise in delivering group programs and ASD may have influenced learning.

In conclusion Project ALLY was demonstrated to be an effective intervention to improve attitudes and behavioural intentions of 4th year secondary school students in Ireland. Gender and previous experience of ASD were not predictive factors for attitude or intentional behaviour. Knowledge of Autism showed a small effect, with those who did not have previous experience of ASD demonstrating the highest gains in knowledge. All of the students in the intervention group demonstrated large gains in knowledge when tested on a measure specifically designed to measure content of the programme. Feedback was very positive from students with and without ASD about the programme. The intervention approach of Project ALLY which combined descriptive, explanatory, directive information and structured contact with peers with ASD was an original method of delivering an autism acceptance programme and it is recommended that this exploratory study be further developed into a full scale randomised control trial.
13 Chapter Thirteen: Conclusion and Findings

13.1 Introduction

This chapter provides an overview of the overall findings from the empirical studies reported in Chapters 8 to 12. Within the complex social environment of secondary school, students with ASD are particularly challenged. Odom (2014) presents the interaction of adolescence, the diagnosis of ASD and new social contexts as the “perfect storm” (p.124) for students with ASD. Greater understanding of these three elements is recognised as imperative to easing the passage through secondary school for students with ASD and ultimately producing better post-secondary outcomes and quality of adult life for these students (Hedges et al., 2014). The challenges of living with ASD are well documented, childhood and the early years are particularly well represented, adolescence and adulthood less well so (Levy & Perry, 2011; Seltzer et al., 2004). This thesis provided a focus of broadening an understanding of the secondary school years, with a specific scrutiny on social and behavioural factors for students with ASD.

A general summary of findings of the research studies will be presented, followed by theoretical implications, cumulative findings and conclusions relating to educational practice. Interpretation of findings will address general limitations and strengths of this body of work and make recommendations for further study.
13.2 Summary and Overview of Studies

The current research comprised two exploratory studies (Chapters 8 and 9), followed by an in-depth analysis of peers’ knowledge, attitude and awareness of ASD and a subsequent experimental study to assess the effectiveness of an intervention to improve these variables (Chapters 10, 11 and 12).

The series of studies reported provide a perspective on the secondary school experience for students with ASD in Ireland. The research began with a parent and teacher perspective of this experience and moved to a narrower focus on peers without ASD, their understanding of the condition, and the social context of secondary school.

13.2.1 Overview of Study 1 (Chapter 8)

The views and perceptions of parents of children with ASD in relation to their experiences particularly around stress and parenting are widely reported (Cadman et al., 2012; Padden & James, 2017; Patton et al., 2018). There are few specific studies of parents’ role and perceptions of the secondary school experience and transition (Dillon & Underwood, 2012; Tobin et al., 2012). The first study aimed to gather parents’ personal accounts of their views of the transition to secondary school and the early secondary school years for their child with ASD within the Irish context. Their views and experiences were interpreted in a pragmatic way to enable other parents take heed of their experiences and understand the pitfalls and enablers to a successful start in secondary school. An enabling perspective is distinctive to this research and it did not attempt to address the parents’ views as necessarily relating to their child’s view, a critique cited towards studies of this type (Carter, 2009). This study was designed as a preliminarily enquiry into the pertinent issues and identified needs for students with ASD attending secondary school. Anxiety was a predominate factor in the experience for both parents and students. Parents identified many ways in which their child’s
experience was enabled and also ways in which they perceived it to be more challenging. There was a view that ASD was poorly understood in many of the schools. They also identified a number of within child factors such as behavioural, social and emotional aspects to their child and their ASD which required unique management and consideration by school personnel. Ultimately, they emphasised their child’s desire to make social connection, to be included and to thrive and attain. This initial study steered the research questions in discovering more about how students experienced the social and emotional challenges of secondary school, the school contexts they were attending and the within school and within student factors that may be influential in the experience of secondary school for those with ASD.

13.2.2 Overview of Study 2 (Chapter 9)

The second study gave a wider view of the secondary school experience for students with ASD in Ireland, measured behavioural and social factors and also attempted to glean more information about teachers and school environments that the students were experiencing. A cross-sectional survey was employed to describe the secondary school experiences for students with ASD in relation to a number of within student factors and within school factors, to describe how well the students had settled and felt established in secondary school. It aimed to explore students’ positive social and problem behaviour from the perspective of teachers and report on experience in teaching students with ASD. This study also aimed to look at any causative relationships between student and school factors and the students’ behavioural profiles. Findings provided an initial and original overview of secondary school for Irish students with ASD and informed about the behavioural and social challenges these students face. Findings reflected literature on adolescence and ASD and the shift towards more internalising problem behaviours.
of anxiety (Bellini, 2006; Simonoff et al., 2008; White et al., 2009). This study demonstrated the low social participation of students with ASD in secondary school and revealed a relationship between higher anxiety and not getting on well with others. The results of the study, particularly in relation to the social experience of school for students with ASD indicated a greater in-depth analysis of the social context of secondary school. The social context is largely made up of other students yet very little is known about their social behaviours towards students with ASD and their understanding of ASD (Humphrey & Symes, 2011). It became apparent that a large gap in the knowledge base of the social secondary school experiences of students with ASD was centred in attempting to find out more about the actions and understanding of peers. This gap in knowledge was addressed through the remainder of the thesis.

13.2.3 Overview of Study 3 and 4 (Chapter 10 & 12)

Chapters 10 and 12 addressed the knowledge, attitudes and intentional behaviours including concepts of neurodiversity of peers without ASD in secondary school. The literature review in Chapter 11 highlighted the weak evidence base for interventions to address and improve understanding of ASD. However, Chapters 10 and 11 demonstrate a crucial need to address these concepts with students without ASD in secondary schools (Bellini, 2006). A cohort of transition year students were examined in relation to self-reported knowledge, attitudes and intentional behaviours including concepts of neurodiversity. The results reflect a broad range of knowledge and attitude. Self-reported attitudes towards ASD were neutral, with reported behavioural intentions high overall, but representing a wide range. Girls were more likely to report positive social behavioural intentions. Knowledge of ASD also varied, but was high overall, particularly for those who had previous experience of ASD. Gaps were identified in the
student understanding of the aetiology of ASD. The students were very unfamiliar with the concept of neurodiversity, but their attitudes reflected a belief that ASD should be recognised as part of a student’s identity. The participants were divided in their beliefs about seeking a cure and teaching a child to be typical. The cohort of students was then randomly assigned participation in an intervention entitled Project ALLY or to a control group. The aim of the intervention study was to explore if their knowledge, attitudes, intentional behaviours and concepts of neurodiversity could be impacted on by the specially designed Project ALLY intervention. Chapter 12 reports the findings of this study. The outcomes of the intervention were very positive with changes in attitude and intentional behaviour demonstrating moderate to large effects. The intervention included a contact aspect to it, which was a novel contribution of the research. Students with and without ASD were enthusiastic and positive in their perceptions of the programme. The findings indicate that a larger scale trial of Project ALLY would be beneficial, as it has the potential to become an evidence-based intervention in schools to improve knowledge, attitudes and behavioural intentions about ASD, and therefore the mutual social experiences of peers with and without ASD.

13.2.4 Conclusion of overview

Overall the findings across the research studies presented in this thesis provide insight into the secondary school experience for students with ASD in Ireland, with a common thread of the social disadvantage student with ASD have and particularly highlighting the role of peers in their social experience of school. There are robust findings in relation to parental views and advice on transitioning to secondary school in Ireland and to the behavioural and social factors at play in the secondary school experience. The findings indicate that anxiety plays a major role in student presentations and may be an
impactful factor on their social experiences. There were strong and positive findings into the effect an intervention for students without ASD can have on their attitudes and intentional behaviours towards their peers with ASD.

13.3 Theoretical and Empirical Implications

The studies reported make a number of theoretical contributions to the existing body of work on secondary school and ASD.

The first study (chapter 8) addressing parental perceptions employed a qualitative methodology. Qualitative studies by their nature are less about making generalisations from findings, and more about reflecting the context (Braun & Clarke, 2006; Clarke, 2013). The context of this study was parents in Ireland of secondary school students with ASD. Their perspectives had not been gathered before, and this study aimed to achieve this. The perspectives of these parents can be viewed as a framework to consider how students with ASD experience the transition to secondary school. Within this framework the parents offered their experience and advice, which can contribute usefully to the wider body of literature on guiding transitions to secondary school for students with ASD. There are very limited theoretical and evidence-based analyses of the transition to secondary school for students with ASD, with mixed finding and reports of how the transition can impact on students and their families (Mandy et al., 2016). With a recent publication of the first attempt to produce an evidence-based transition programme, The Systemic Transition in Education Programme for Autism Spectrum Disorder (STEP-ASD), it is acknowledged that perspectives on this time in the life of a student with ASD are vital to informing the theoretical and practical development of these types of intervention (Mandy et al., 2015;
Mandy et al., 2016). Furthermore, these programmes need to reflect cultural contexts and experiences, which this study of Irish parents can contribute to.

The second study (chapter 9) developed understanding and provided real insights into how students are experiencing and presenting in secondary school. In some ways it also presents more theoretical questions than answers in this widely under-researched space. It combined two areas of theory namely: 1) the presentation of challenging and social behaviour in adolescents with ASD, and 2) the experience of students in the secondary school context. With greater theoretical understanding of how influential the school context can be on the presentation of behaviour and positive outcomes for adulthood (Woodman et al., 2015) trying to address these factors together becomes an important contribution to the theory and knowledge base. Dynamic systems theory provides a lens to view the development and the relationship between individuals and their context, is a contemporary and well-developed perspective (Bronfenbrenner, 2005). It is less widely applied to students with ASD, as studies often address deficits or presentations in isolation of context. School environment is considered one of the most relevant influencers on development. Prior research has demonstrated that the student’s secondary school experience can be challenging, yet educational context is underexplored as a contributory factor to positive outcomes in adult life for those with ASD (Woodman et al., 2015). Study 2 contributed valuable description of this experience for a cohort of Irish adolescence with ASD. Findings from the study indicate that those who were fully integrated in mainstream classrooms were the most socially confident, although this may be viewed as the group who were potentially in least need of support, there is also a perspective that inclusive school experiences drive these improved skills and ultimately predict better outcomes (Humphrey & Symes, 2010b, 2011; Woodman et al., 2015). The findings in relation to anxiety are also a useful
contribution to theory. The nature of this anxiety is important, and there are some indicators from findings that it may be socially-based and impacting on their ability to access social situations or groups. Social anxiety is also driven by negative social experiences, creating a negative feedback loop (Bellini, 2006). This study highlights the social and behavioural challenges in the context of school. Understanding these challenges and the impact on school participation can contribute to the development of specific evidence-based interventions which are feasible within schools.

Study 3 and 4 (chapter 10 & 12), bring about a conceptual advancement in the understanding of the social context of peers in the secondary school, and how their knowledge and attitudes about and towards their peers with ASD can be effectively improved. More recent studies have demonstrated growing awareness and knowledge, but also gaps and misconceptions (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013; Dillenburger et al., 2017; Dillenburger et al., 2015). Findings reported from these studies have demonstrated this to be the case in Irish secondary school students, but also that these outcome variables can be impacted on. The importance of autism acceptance as a contributing factor to social experience and positive mental health is beginning to emerge within the theoretical literature (Cage et al., 2017). There is also a growing recognition that interventions which address environmental influences on students with autism, also need to be evidence-based and established (Mandy et al., 2015). The literature review in Chapter 11 demonstrates that the theory base is weak in reference to intervention but that explanatory and descriptive information are vital aspects to any educational programme. Study 4 demonstrated that contact is also an important and influencing factor. The contact factor in the Project ALLY intervention was structured and supported. Allport’s (1954) contact theory asserts that contact should lessen negative attitudes. However, the quality and nature of the experience should also be
taken into account (McManus et al., 2010). Study 4 demonstrated a structured and positive contact experience for students with and without ASD, with outcomes reflecting large changes in behavioural intentions of the students without ASD. With regard to attribution theory (Juvonen & Weiner, 1993) and the theory of planned behaviour (Ajzen, 1991), both of which are purported to explain negative attitudes and intentional behaviours to peer who are perceived as different, the findings of Study 4 further corroborate this. In terms of attribution theory, the students demonstrated more positive attitudes with greater understanding of the reasons their peers were in some way different. In relation to the theory of planned behaviour, it is hypothesised that the more effort a student has to make to carry out an action e.g., a social approach to a student with ASD, the less likely it is they will carry out it out. The intervention allowed students to learn communication strategies in order to make social contact, and also removed the physical barrier of the classroom in order for them to be able to carry it out. Finally, Study 4 introduced concepts of neurodiversity to secondary school students. This was an original approach and reflective of contemporary biopsychosocial views of autism (Hollenweger & Moretti, 2012; Kapp et al., 2013). Students demonstrated that they were able to conceptualise this theory and reflected attitudes in tune with this.

13.4 Central concepts and cumulative findings

In order to synthesise and conclude the thesis, the four studies were examined as one programme of research which could contribute to a greater understanding of the secondary school experience for students with ASD in Ireland. Four central concepts which reflect the findings across all of the studies were identified as: 1) communication; 2) anxiety; 3) inclusion, and 4) knowledge and understanding.
13.4.1 Communication

Communication as a means to information, as a social interaction and as a core difficulty for students with ASD is highlighted throughout the empirical studies. Parents were very strong on this, and findings from Chapter 8 indicate a perspective that positive and open channels of communication between schools and home is regarded as a vital aspect to a successful transition to secondary school. The findings in Chapter 9 reflect the core social and communication deficit of ASD and indicate that this is reflected in students’ experience of school. With almost 70% of students in study 2 reported to have some level of difficulty with conversational skills. These difficulties related to students being less likely to join in group activities and make friends. Other studies have demonstrated that lack of social opportunity can directly impact on students with reports of loneliness and a desire to be able to make friends (Lasgaard et al., 2010) and also increase the risk for depression and social anxiety (Simonoff et al., 2008; White et al., 2009). Indeed, findings from Study 2 confirmed this high rate of anxiety and it relationship to social confidence. These findings indicate that the implementation of social communication interventions is a necessity, and some of the most successful interventions involve peers and peer mediated interventions (Bambara et al., 2016). However, in order to achieve this, there is a requirement for peers who know and understand ASD and have confidence in their own communication skills. Studies 3 and 4 in this thesis addressed this at the level of finding out more about students’ knowledge and understanding and implementing an intervention which gave directive instruction and strategy to students without ASD in communicating with their peers with ASD. Findings positively indicated that this type of intervention was effective to this end and provided structured opportunities for both groups of students to communicate.
13.4.2 Anxiety

Anxiety disorder co-occurs with ASD and has been reported repeatedly in the literature (e.g., Kim et al., 2000; Mayes, Calhoun, Murray, Ahuja, & Smith, 2011; Simonoff et al., 2008; White et al., 2009; Witwer & Lecavalier, 2010), with a specific view that anxiety increases with development and adolescence (Ambler et al., 2015; Hebron & Humphrey, 2014b; White et al., 2009). Study 2’s findings confirmed this in a sample of Irish students. Reported anxiety in Irish schools is as high as other studies (Lecavalier, 2006). The relationship between anxiety and getting along with others was an important finding within the school setting. The least anxious students were the ones most likely to get along with others. The model of social anxiety proposed by Bellini (2006) mirrors this finding and implies that weaker social skills influence the development of social anxiety, which is being played out in the school setting (Bellini, 2006). The suggestion that positive social interaction can improve this is linked to the findings in Study 4 (Chapter 12), and the development of an intervention (Project ALLY) which encourages positive interactions between those with and without ASD. Anxiety was also a prominent feature and finding in Study 1 involving parents. It was presented by this group of parents as a real sense of unease about whether schools were competent in dealing with their children and an acknowledgment that a student to school mismatch could have stressful consequences for the child and family (Cadman et al., 2012; Dillon & Underwood, 2012; Kenny et al., 2005; Mount & Dillon, 2014).

13.4.3 Inclusion

As Dillenburger et al. (2017) indicate, for inclusion in schools to be a success supports and positive peer attitudes are implied. There is a real concern that inclusive policies are
not implemented in a fashion which promotes inclusion beyond the physical proximity of students (Asmus et al., 2017; Carter et al., 2014). Parents in Study 1 also found this to be the case, with a specific focus on social inclusion and a noticeable absence of support for social skills or strategies for making social connections. Findings also confirmed this lack of inclusion in activities outside the classroom, by the low numbers reporting to participate in extra-curricular activities in Study 2. It was reported that students with ASD were also physically separated with half of them attending classes outside of the mainstream for some or all of their time in school in Study 2. The attitudes of students without ASD also reflected this experience, Study 3 found that lowest mean attitude score was for the statement “children with autism should be fully integrated into mainstream classes”. This is perhaps the question which the students had most direct experience of having observed students in their own school participate in separate educational and social activities. Study 4 demonstrated that student attitudes changed following participation in Project ALLY.

13.4.4 Knowledge and Understanding.

Parents in Study 1 relayed a concern in relation to school personnel’s knowledge and understanding of ASD, a finding which is similar to other studies of parental perceptions (Tobin et al., 2012). The teachers in Study 2 reported to be quite familiar with ASD, but less so with ABA and specific training associated with this. Understanding ASD is one thing, but this needs to be backed up with skills and abilities to carry out evidence-based educational interventions. The lack of teacher training in this area is an important finding from Study 2 and echoes international concern that students with ASD may not receive these types of intervention in secondary schools (Kucharczyk et al., 2015).
Related to knowledge and understanding of peers, the findings from Study 3 and 4 highlight how students in Irish secondary schools have a good knowledge base, and mainly positive attitudes in relation to ASD. Project ALLY enabled a demonstration that this knowledge base and understanding could be further improved, and that students benefited from explanatory, descriptive and direct information about ASD, as well as gaining social experiences with students with ASD in their own school setting.

13.5 Practical Implications and Further Research

The synthesis of these central concepts leads to practical implications and recommendations for further research.

The varied and ad hoc nature of communication experiences of parents with secondary schools, and the recent acknowledgement that transition to secondary school programmes can be an evidence-based way of ensuring a positive transition experience (Mandy et al., 2015), implies that communication strategies and policies should form an integral part of any transition programme. Demarking lines of communication and signposting to parents’ ways in which they can communicate with secondary schools may be a useful way to alleviate concerns.

There is a challenge to involving students with ASD in more social communication activity in school setting which needs to be addressed across secondary schools. There is a variety of methods and recommendations reported in the literature as to how this can be done, with promising findings from peer network intervention and the use of preferred interests (Asmus et al., 2017; Carter et al., 2014; Koegel et al., 2013). Examining the feasibility of these types of programmes in Irish secondary schools would be a useful research exercise. The promising findings from Project ALLY also indicate its shared social and learning sessions could be further developed.
and researched as a potential extension to this aspect of the programme. Observational analysis and measurement of social communication variables in the students with ASD would also be required.

Anxiety was highlighted as a key feature of the secondary school experience for students with ASD. It is recommended that further research addresses this by specifically examining the presentation of anxiety within school settings and secondly by addressing how best to manage it. Study 2 indicates that anxiety and related behaviour is an observed phenomenon in the school experience of students with ASD. Further studies specific to the school environment and predictive factors for anxiety responses in students would provide valuable information. The link between anxiety and social processes also warrants further investigation. When assessed in terms of the research findings and suggestions in the literature that negative social experiences drive it further (Bellini, 2006), interventions which target both students with and without ASD, such as Project ALLY may be useful to this end.

There is a challenge to improve teacher training and familiarity with evidence based educational interventions for secondary school students with ASD. Findings in this study lacked detail but did indicate a lack of awareness and training in the teacher sample. Fennell and Dillenburger (2018) highlight the issue in greater detail, and recommend quality control and teacher training, which is overseen and reflective of international standards. Part of this call for training should also include addressing inclusive practice and policy. Findings from this study indicate students are not having inclusive school experiences, with segregation and limited social inclusion reported. There are wide ranging policy and practice implications to this which will need to be addressed through the NCSE in Ireland.
The Project ALLY intervention and exploratory study provide positive preliminary findings that impact on students’ (without ASD) knowledge, understanding and intentional behaviours about and towards their peers with ASD, including concepts related to neurodiversity. It is important that this intervention be further trialled in order to establish an evidence-base for its implementation. Part of this will involve feasibility and fidelity checks so that teachers or other school personnel can take on its delivery. Maintenance and follow-up data will also need to be incorporated. The inclusion of more robust and reliable measurement including observational data and implicit measures of attitude is also recommended.

13.6 Strengths and Limitations

As limitations to each study have been presented in separate chapters, an overview of general limitations and strengths is given. The studies in this thesis have strength in their breadth and overall analysis of the secondary school for students with ASD in Ireland. They represent an original contribution to the knowledge base around several aspects of this experience. The studies were all relatively small in terms of their sample size and this has been acknowledged as a limitation across each one. There was a challenge to recruitment; the enthusiasm of stakeholders was not reflected in the take up of research participants. Possible causes for this may include, an apathy towards research and its merits (perhaps due to a sense of being over researched on). Related to this was an obvious greater concern about individual need and service provision over involvement in a research process with no real individual gain.

The research was conducted by a lone researcher, in terms of the intervention research this created a challenge for the measurement and delivery of programmes. The
reliance on teaching staff for randomizing the sample, supervising data collection and scheduling of sessions causes practical and feasibility challenges to the study design. Measurement was all self-report, which is of its nature known to have some reliability and social desirability biases (Van de Mortel, 2008).

The absence of input of students with ASD is also a limitation to this research. Although they participated in Project ALLY and contributed to social validity, their first-hand accounts of secondary school were not part of this research. Their parents and teachers reported on experiential factors. Although it can be argued that none of the research projects aimed to capture their voice, it remains a recommendation for future and follow on studies that this be included.

13.7 Conclusion

The endeavours made by this body of research were to advance understanding and knowledge relating to the social experience of secondary school for students with ASD. Four studies were outlined which examined parental views on the transition to secondary school, the within student, within school and behavioural factors influencing the experience of school, and peers without ASD knowledge of autism and their attitudes and behavioural intentions towards peers with ASD. It demonstrated the effectiveness of a tailored intervention for students without ASD on their knowledge, attitudes, intentional behaviours and their concepts of neurodiversity. The intervention was inclusive of students with ASD and gave the opportunity for students with and without ASD to have social and learning experiences together. This novel factor to the intervention was demonstrated to be a vital aspect in the effect of the intervention.

The research addressed some important gaps in knowledge relating to effective intervention to improve attitudes and intentional behaviours of secondary school
students without ASD. It provided a novel insight into students in secondary school with ASD from a positive and problem behaviour perspective and considered relationships between these and within student and school factors. It has provided a viewpoint on this formative time in the life of a student with ASD and added to the knowledge base which will inform further development of interventions and supports for this group of students. It is expected that Project ALLY will be further evaluated and tested with the anticipation that it can be investigated as an evidence-based intervention for use in secondary schools. This body of research also highlights the continuous efforts which need to be made to fully support and understand students with ASD in secondary schools and promote improved outcomes and quality of life.


doi:10.1177/1362361315597525


doi:10.1177/0741932516672067


Fondelli, T., & Rober, P. (2016). ‘He also has the right to be who he is …’. An exploration of how young people socially represent autism. *International Journal of Inclusive Education, 21*(7), 701-713. doi:10.1080/13603116.2016.1252431


Swaim, K. F., & Morgan, S. B. (2001). Children's attitudes and behavioral intentions toward a peer with autistic behaviors: Does a brief educational intervention have
doi:10.1023/A:1010703316365

doi:10.1177/0143034310382496


Taib, F., & Yusoff, M. S. B. (2014). Difficulty index, discrimination index, sensitivity and specificity of long case and multiple choice questions to predict medical


Appendix A: Letters, Consent, Participant Information, demographic questionnaire and interview schedule - Study 1
Parents’ perspectives on the transition of children with Autistic Spectrum Disorder (ASD) into secondary school.

**What is the Study about and what is its purpose?**

This study is about trying to find out about children in Ireland with ASD who have made the move to secondary school, from their parents’ perspective or view point. This is an important, exciting and often challenging time for children / adolescents and their families, but we know very little about how children with ASD experience this transition. The study will take the form of an interview with parents. It is expected that this study will highlight how children with ASD can be supported into secondary school, and what can hinder their progress and participation in secondary school. It is hoped the study will help to improve policy and support for children with ASD in secondary school. This study will also inform a larger project to investigate the experiences of children with ASD and their transition into secondary school Ireland. This is being completed in the Children’s Research Centre, Trinity College Dublin (TCD) and supervised in the School of Psychology, TCD.

**What is involved?**

You can participate in this study if you are a parent of a child with ASD in mainstream secondary school (including a special unit or class). You will be invited to take part in an interview that will be held in a suitably convenient venue and time. You will be asked to discuss your experiences of your child’s transition to secondary school. The discussion is not limited to any specific aspect of the transition and will be a forum to raise and discuss issues, views and experiences. Katie Cremin PhD student in School of Psychology TCD and lecturer in Discipline of Occupational Therapy TCD will facilitate the interview. It will be tape-recorded, transcribed to print and analysed. You will receive a copy of the transcription and the researcher’s analysis of the interview. You can provide verbal or written comments on this. A final copy of the research report will be made available to you if you wish to receive it.
Confidentiality

No personally identifiable information will be included in the transcripts. Personally identifiable information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted files on password protected computers. If you wish to access your information at any stage, it will be made available to you.

Voluntary participation and withdrawal

If you decide to volunteer to participate in this study, you may withdraw at any time without consequence.

What are the benefits of taking part?

The study is aiming to add to the limited knowledge base around the transition to post primary education for children with ASD in Ireland. It is hoped that it will explore the current context for children with ASD and highlight areas for improvement in terms of supporting the transition and the child’s overall participation in school life.

What are the risks or disadvantages of taking part?

The risks associated with participating in this study are minimal. It is possible you may find discussing your views and experiences stressful or difficult. You are obviously free to leave if you wish and information in relation to support can be made available to you.

Ethical Permission

This research project has research ethics committee approval from the School of Psychology, Trinity College Dublin

Further Information

You can get more information or answers to further questions about the study, your participation in the study, and your rights from Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, or her supervisors Dr Kirsten Maglieri, k.maglieri@tcd.ie, ph 01 8961175 and Dr Michael Gordon, gordonms@tcd.ie, ph 01 8962969, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

If the study team learns of any important new information that might affect your desire to remain in the study, you will be informed at once.

Contact details: Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

Academic supervisors: Dr Kirsten Maglieri, k.maglieri@tcd.ie, ph 01 8961175 and Dr Michael Gordon, gordonms@tcd.ie, ph 01 8962969, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

I have read and understood the information leaflet. I consent to taking part in this research project. I understand that agreeing to take part means that I am willing to:

- Take part in an interview / discussion to gather the views and experiences from a parent’s perspective about the transition to secondary school for children with Autistic Spectrum Disorder.
- Give my verbal or written feedback to the researchers after the group.
- Make myself available for a further interview in the unlikely event that this will be required.
- Allow the information gathered to be used in the research project which may be published in a journal or at a conference.
- Be contacted in the future if my information is wanted for further research.

I understand that all information I give will be kept confidential. I understand that I can withdraw or be withdrawn by the researchers at any stage without being penalised or disadvantaged in any way.

I understand that there is a risk that I could become upset by the issues raised during the research project. I understand that I can leave the interview if I want
to and the researchers will provide support or find the relevant support for me in this instance.

DECLARATION:
I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Please fill in the following if you consent to take part in the research project:

PARTICIPANT'S NAME: ............................................................... 

PARTICIPANT'S SIGNATURE: ............................................................
Date: .................................. 

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURES ....................................................
Date: ............... 

Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, or her supervisors Dr Kirsten Maglieri, k.maglieri@tcd.ie, ph 01 8961175 and Dr Michael Gordon, gordonms@tcd.ie, ph 01 8962969, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2
25/04/2012

Dear Parent / caregiver,

I am undertaking a PhD research project looking at the transition to secondary school for students with Autistic Spectrum Disorders (ASD). I would like to set up some interviews with parents of students with ASD in secondary school about their experience of the process. The factors which enable a student to make a successful transition are of particular interest to me.

If you would be interested in participating in an interview, or would like more information about the project, I would be delighted to hear from you.

e.mail: cremink@tcd.ie or phone: 01 8963813

Yours sincerely,

Katie Cremin
Transition to Secondary School Study

Please complete the following confidential questionnaire if you would like to be involved in the focus group research and return via e-mail or in the SAE.

Name of Parent:

County:

How would you like to be contacted? Please provide details

e-mail:
Mobile Phone:
Phone:
Post / Address:

The following questions are in relation to your child who has a diagnosis of Autistic Spectrum Disorder and is attending 1st or 2nd year Secondary School.

Child’s Date of Birth:
Year in School:

How would you describe your child’s schooling (please tick)
a) Full time mainstream secondary school
b) Part time / shorter hours mainstream secondary school
c) Full time special class or unit in secondary school
d) Part time mainstream and part time special unit or class in secondary school
e) Other please give details:

Does your child have a special needs assistant (SNA)?
Please give details…

Does your child receive any resource teaching or individual tuition?
Please give details…

Does your child attend a service for children with ASD?
Provide details if you wish….
Does your child receive support in school from a health care or similar service? □
Provide details if you wish…..

Does your child have an Individualised Educational Plan (IEP) □
Who is responsible for this plan?

Please provide further details if you wish…. 

What type of primary education did your child come from – please tick
 a) Special school □
 b) ABA school / pilot school □
 c) Autism unit / class in a mainstream school □
 d) Mainstream primary school □
 e) Other □ please give details:

Did your child have an IEP during their primary education? □
Please give details if you wish…

How was your child’s transition to secondary school managed / prepared for
 a) Group transition programme □
 b) Individual transition programme or plan □
 c) Informal liaison between schools □
 d) Parent led liaison between schools □
 e) Same as all the other children in primary school □
 f) No transition planning □
 g) Other □

Please give more details if you wish…….. 

What is your child official diagnosis / diagnostic category?

Thank you

Any further comment………..
Interview schedule / Guide
Transition to secondary school and ASD
Focus group research

Introduction and welcome
Welcome and thanks for coming. Appreciate your contribution. This is a discussion, so there are no right or wrong answers. I am very interested in your experiences of your child’s transition to secondary school, and any thoughts, feeling or opinions you have on the matter. The main purpose of this interview is to gather your perceptions and views as a parent of a child with ASD on how the transition was for them, and what you perceive as the important factors to making a successful transition and settling into secondary school.
There are a couple of important guideline I would appreciate if you could follow during the course of the interview.
RUN THROUGH THE FOLLOWING
- No need to speak in any particular order
- When you have something to say please do so
- Please try not to interrupt or jump in when someone else is talking
- Trying to get everybody’s point of view
- Try not to put others down even if you don’t agree with them
- If we veer of topic, I may have to veer discussion back to topic
- Any questions??

Warm up
Set tone – some of you may know each other, others not
Introduce selves and tell us a little about your child and what type of primary school they transitioned from.

Clarification of terms
Discuss terms of ‘transition’, ‘mainstream’, ‘participation in school’, ‘supports’
– reference time frames, types of mainstream education, what constitutes participation in education, types of supports offered to pupils.

Easy and non-threatening questions
Initial questions to allow people feel more comfortable to give their point of view – participants may answer form a personal perspective of more generally.

- What do you think factors are which make a successful transition for a child with ASD into secondary school?
- What do you think factors are which make a successful transition for a child with ASD into secondary school?
- What are the reasons a child may find it hard to settle or participate in school life?
- What may make it easier?
- Discuss factors in the classroom – teachers, supports, curriculum
Discuss factors outside of the classroom - e.g., social and physical environment, peers groups, sport/extra curricular

**More difficult questions**
Probes more towards own personal opinion and experiences
- From your own child’s experience how was transition managed – who was involved – how supported?
- Factors in choosing secondary school for your child
- Have they settled – factors in this?
- How could this transition be managed differently
- Do you think you right environment for their needs
- Do you think their primary education is a factor in how they are settling into secondary school

**Wrap up and Member check**
*Thanks group for all their input – coming close to the end of the discussion.*
*I’m going to try and summarise key things I have heard…..*

**Would you like to add or correct any of this?**

- *Mention issues which have been brought up but not covered by discussion fully*

- Verify how members of the focus group feel about various issues by reflecting on key points and looking for people to agree or disagree with them

**Closing statement and de-brief**
*Thankyou for participating today. Can I remind you that this interview has been taped and the interview will be transcribed and anonymised for the purpose of analysing the data. All information and data pertaining to this will be kept securely (data protection). Please respect the confidentiality of group members and refrain from discussing this focus group with others. Please take a copy of de-briefing information. Thank you again……*

**Prompts:**
Moving away from tangent topic – “thanks for the interesting input, we need to consider another question……”
Moving back onto topic – “let’s get back to discussing the question that relates to…..”
Encouraging participation - “you mentioned xxxxx, could you tell us a little more about that”
- ‘xxxx, what is your opinion on this?”
Probe for clarifying statements - e.g “what do you mean by strongly in this instance?”
Appendix B: Letters, Consent, Participant
Information and questionnaires / measures
- Study 2
Dear Parents / Caregiver,

You and your son/daughter are invited to participate in a study about participation in secondary school for students with Autistic Spectrum Disorder. It aims to look at this important time in a student’s life, with a particular focus on behaviour and social competence. It will also look at the risk factors for difficulties in these areas at school.

This study involves the parent completing and questionnaire about their child’s ASD and schooling. The questionnaires should take no longer than thirty minutes to complete and can be done via email or online (www.teenswithasdinireland.com). It also involves giving permission for a nominated teacher or school personnel completing an anonymous questionnaire about your son or daughter (The Nisonger Child behaviour Rating Form – Teacher Version) and some information about their school and their familiarity with ASD and ABA.

If you would like to participate or would like more information please email cremink@tcd.ie or call 01 8963813. Or simply log onto www.teenswithasdinireland where you can find all the study information and complete the questionnaire.

This study forms part of a larger PhD project looking at the experience of secondary school for students with ASD. It is intended to follow up this phase of study with gathering some information from the students themselves (you can indicate your interest or not in this phase following completion of the questionnaires).

If you have any further questions, comments or feedback, please do not hesitate to contact me.

Your completion of the questionnaires is completely voluntary. You can withdraw from the study at any point without penalty.

Yours sincerely,

Katie Cremin
The experience of Secondary School for students with Autistic Spectrum Disorder (ASD)

Social competence and challenging behaviour study

What is the Study about and what is its purpose?
This study is about finding out more in relation to students with ASD who are attending mainstream secondary schools in Ireland. We know very little about how students with ASD progress and participate in secondary schools. This study will focus on teacher’s observations of students’ behaviours and social competence in the school environment. The study is designed to look at factors which relate to the students’ ability to integrate and participate in secondary school. It is hoped the study will help to improve policy and support for children with ASD in secondary school. This study is part of a PhD which is being completed in the Children’s Research Centre, Trinity College Dublin (TCD) and supervised in the School of Psychology, TCD.

What is involved for the student’s teacher?
You are being asked to complete a questionnaire about the student’s behaviour and social competence, called the Nisonger Child Behaviour Rating form*, you will also be asked to complete a short questionnaire with basic information about the school i.e., size, resources available to the student etc., and a familiarity with ASD and applied behavioural analysis scale. The questionnaires will be posted to you once the student and parents have consented to participate. You will be asked to return the completed questionnaire in a stamped addressed envelope directly to the researcher. The teacher does not have to report any personally identifiable information about themselves or the school.

*In the event that measures come up strongly with serious self injurious behaviours or behaviours of serious concern to the students, family or teachers well being – A protocol will be put in place to offer advice in seeking assistance for these behaviours.

Confidentiality
No personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted files on password protected computers. You have the right to access your personal data at any time under the Freedom of Information Act (1997). The information you provide will be stored at Trinity College Dublin for a period of 10 years. You may request access to your information at any time of the study or at any point during the 10 year period. Please also note that if information emerges that raises a serious concern for the safety or well-being of any individual, the researcher will be required to report this through the appropriate channels.
Voluntary participation and withdrawal
If you decide not to participate in this study, you may withdraw at any time without consequence; you may also request any data pertaining to you be removed from the study prior to the point of analysis and submission of the research report or publication (i.e., September 2016).

What are the benefits of taking part?
The study is aiming to add to the limited knowledge base around participation in secondary school for students with ASD in Ireland. It is hoped that it will explore the current context for students with ASD and highlight areas for improvement in terms of supporting the school and student.

What are the risks or disadvantages of taking part?
The risks associated with participating in this study are minimal. If you find any aspect stressful or difficult, you can discuss it with the researcher and you are obviously free to withdraw from the study at any point. Information in relation to support can be made available to you also.

Ethical Permission
This research project has research ethics committee approval from the School of Psychology, Trinity College Dublin.

Further Information
You can get more information including copies of the questionnaires or answers to further questions about the study, your participation in the study, and your rights from Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, or her supervisor Dr Olive Healy, olive.healy@tcd.ie, ph:8961175 School of Psychology, Aras an Phiarcaigh, Trinity College, Dublin 2
The experience of Secondary School for students with Autistic Spectrum Disorder (ASD)

*Social competence and challenging behaviour study*

**What is the Study about and what is its purpose?**

This study is about finding out more in relation to students with ASD who are attending mainstream secondary schools in Ireland. We know very little about how students with ASD progress and participate in secondary schools. This study will focus on teacher’s observations of students’ behaviours and social competence in the school environment. The study is designed to look at factors which relate to the students’ ability to integrate and participate in secondary school. It is hoped the study will help to improve policy and support for children with ASD in secondary school. This study is part of a PhD which is being completed in the Children’s Research Centre, Trinity College Dublin (TCD) and supervised in the School of Psychology, TCD.

**What is involved?**

As the parent of a student in secondary school, you and your child are being asked to give your consent and assent to your child’s teacher completing a questionnaire about your child’s social competence and behaviour in school - called the Nisonger Child Behaviour Rating form*. Parents are also being asked to complete the Social Communication Questionnaire in relation to their child’s ASD and some brief demographic information e.g., rural or urban and type of secondary school. You choose to give permission for the researcher to contact your child’s teacher directly. All questionnaires will be sent in the post to the address which you provide along with stamped addressed envelopes (SAE) for their return. A final copy of the research report will be made available to you if you wish to receive it.

*in the event that this measures comes up strongly with serious self injurious behaviours or behaviours of serious concern to the student, family or teachers well
being – A protocol will be put in place to offer advice in seeking assistance for these behaviours.

Confidentiality
No personally identifiable information will be included in the research reports. Personally identifiably information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted files on password protected computers. You have the right to access your personal data at any time under the Freedom of Information Act (1997). The information you provide will be stored at Trinity College Dublin for a period of 10 years. You may request access to your information at any time of the study or at any point during the 10 year period. Please also note that if information emerges that raises a serious concern for the safety or well-being of any individual, the researcher will be required to report this through the appropriate channels.

Voluntary participation and withdrawal
If you decide not to volunteer to participate in this study, you may withdraw at any time without consequence; you may also request any data pertaining to you or your child be removed from the study prior to the point of analysis and submission of the research report or publication (i.e., September 2016).

What are the benefits of taking part?
The study is aiming to add to the limited knowledge base around participation in secondary school for students with ASD in Ireland. It is hoped that it will explore the current context for students with ASD and highlight areas for improvement in terms of supporting the school and student.

What are the risks or disadvantages of taking part?
The risks associated with participating in this study are minimal. If you find any aspect stressful or difficult, you can discuss it with the researcher and you are obviously free to withdraw from the study at any point. Information in relation to support can be made available to you also.

Ethical Permission
This research project has research ethics committee approval from the School of Psychology, Trinity College Dublin.

Further Information
You can get more information including copies of the questionnaires or answers to further questions about the study, your participation in the study, and your rights from Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, Dr Olive Healy, olive.healy@tcd.ie, ph:8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

If the study team learns of any important new information that might affect your desire to remain in the study, you will be informed at once.
Study title: The experience of Secondary School for students with Autistic Spectrum Disorder (ASD) - Social competence and challenging behaviour study

Contact details: Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

Academic supervisors: Dr Olive Healy, olive.healy@tcd.ie, ph:8961175 ph 01 8962969, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

I have read and understood the information leaflet. I consent to taking part in this research project. I understand that agreeing to take part means that I am willing to:

- Complete the Nisonger Child Behaviour Rating form in relation to the named student and return in the SAE provided to the researcher.
- Complete the familiarity with ASD and ABA rating scale.
- Provide some demographic information about the school.
- Allow the information gathered to be used in the research project which may be published in a journal or at a conference.
- Be contacted in the future if my information is wanted for further research.

I understand that no personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted files on password protected computers. If I wish to access my information at any stage, it will be made available to me I have the right to access my personal data at any time under the Freedom of Information Act (1997). The information I provide will be stored at Trinity College Dublin for a period of 10 years. I may request access to my information at any time of the study or at any point during the 10 year period. If information emerges that raises a serious concern for the safety or well-being of any
individual, the researcher will be required to report this through the appropriate channels.

I understand that there is a risk that I could become upset by the issues raised during the research project and the researchers will provide support or find the relevant support for me in this instance.

I understand that I can withdraw from the study if I want to and that I may also request any data pertaining to me be removed from the study prior to the point of analysis and submission of the research report or publication (i.e., September 2016).

DECLARATION:
I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Please fill in the following if you consent to take part in the research project:

PARTICIPANT'S NAME
(print):..............................................................................

PARTICIPANT'S SIGNATURE:............................................................
Date:.................................

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURES..............................................
Date:......................
Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, or her supervisor Dr Olive Healy, olive.healy@tcd.ie, ph: 8961175 School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2
Parent/guardian

**Study title:** The experience of Secondary School for students with Autistic Spectrum Disorder (ASD) - *Social competence and challenging behaviour study*

**Contact details:** Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

**Academic supervisors:** Dr Olive Healy, olive.healy@tcd.ie, ph:8961175 and Dr Michael Gordon, gordonms@tcd.ie, ph 01 8962969, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

I have read and understood the information leaflet. I consent to taking part in this research project. I understand that agreeing to take part means that I am willing to:

- Complete the Social Communication Questionnaires about my child.
- Provide some demographic information about my child and their school.
- Give permission for my child’s teacher to be contacted to complete a questionnaire about my child.
- Complete a contact details sheet.
- Allow the information gathered to be used in the research project which may be published in a journal or at a conference.
- Be contacted in the future if my information is wanted for further research.

I understand that no personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted files on password protected computers. If I wish to access my information at any stage, it will be made available to me. I have the right to access my personal data at any time under the Freedom of Information Act (1997). The information I provide will be stored at Trinity College Dublin for a period of 10 years. I may request access to my information at any time of the study or at any point during the 10 year period.
If information emerges that raises a serious concern for the safety or well-being of any individual, the researcher will be required to report this through the appropriate channels.

I understand that there is a risk that I could become upset by the issues raised during the research project and the researchers will provide support or find the relevant support for me in this instance.

I understand that I can withdraw from the study if I want to. I may also request any data pertaining to me or my child be removed from the study prior to the point of analysis and submission of the research report or publication (i.e., September 2016).

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Please fill in the following if you consent to take part in the research project:

PARTICIPANT'S NAME
(print):.................................................................

PARTICIPANT'S SIGNATURE:.............................................................
Date:.................................

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR’S SIGNATURES.............................................
Date:..................
Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, or her supervisors Dr Olive Healy, olive.healy@tcd.ie, ph:8961175 and Dr Michael Gordon, gordonms@tcd.ie, ph 01 8962969, School of Psychology, Aras an Phiarasigh, Trinity College, Dublin 2
Dear Teacher / School personnel,

You are the nominated teacher or nominated school personnel identified by (with their consent) to complete an anonymous questionnaire about This questionnaire is called The Nisonger Child behaviour Rating Form – Teacher Version. You are also being asked to give some information about the school and your familiarity with Autistic Spectrum Disorder and Applied Behavioural Analysis. The questionnaires should take no longer than thirty minutes to complete. You can return the forms with the stamped addressed envelopes provided.

This is a study about participation in secondary school for students with Autistic Spectrum Disorder. It aims to look at this important time in a student’s life, with a particular focus on challenging behaviour and social competence. It will also look at the risk factors for difficulties in these areas at school.

Your participation is greatly appreciated. Please return the consent form and completed questionnaires. Please be assured that your contact details are for this purpose only and will be stored securely and separately to the anonymous information you provide on the questionnaires.

There is more detailed information about the study for you in the enclosed information leaflets. If you have any further questions, comments or feedback, please do not hesitate to contact me. I have also enclosed some brief information sheets about the study. I’d be delighted if you could distribute these to any other parents of students with ASD who may have an interest in participating in the study.

If you would prefer to complete this questionnaire via email, please just contact me at cremink@tcd.ie and I will forward you an e-copy of the questionnaires.

Your completion of the questionnaires is completely voluntary. You can withdraw from the study at any point without penalty.

Yours sincerely,

Katie Cremin

Assistant Professor and PhD student
Discipline of Occupational Therapy, School of Psychology and Children’s Research Centre, Trinity College Dublin.
The Experience of Secondary School for Students with Autistic Spectrum Disorder (ASD)

We know very little about how students with ASD progress and participate in secondary school. This study will focus on student’s behaviours and social competence in the school environment.

This study is part of a larger PhD project looking at secondary school experiences for students with ASD. As a parent you are be asked to complete a questionnaire in relation to your child’s ASD and schooling. You and your child are also being asked to give your consent to allow a nominated teacher be asked to complete a questionnaire about social competence and behaviour in school. The parent questionnaire and consent can be completed online.

All information will be treated as confidential.

This research project has research ethics committee approval from the School of Psychology, Trinity College Dublin.

If you are interested in participating or would like to hear more about the study.

www.teenswithasdinireland.com
contact Katie Cremin at cremink@tcd.ie or 0878161845

Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813. Supervisor: Dr Olive Healy, olive.healy@tcd.ie, ph:8961175 School of Psychology, Aras an Phiarasigh, Trinity College, Dublin 2
My name is Katie Cremin, I work and study at Trinity College Dublin. I am doing a research project about students who are in secondary school. I would like give you some information about this project.

I would like to send a questionnaire to your parents. The questions they will answer are about you, how you communicate and how you act socially.

For example:

Do you have a to and fro ‘conversation’ with him/her that involves taking turns or building on what you have said?

I would also like to send a questionnaire to your school for one of your teachers to answer. The questions they will answer are about you, how you behave and how you act socially.

For example:

Have you noticed that he/she has difficulty concentrating?

These questionnaires are anonymous and confidential. That means nobody will know or tell anybody that they have completed the questionnaires. Your name or school will not be on any of the questionnaires.

A large number of students are being asked be part of this study. All this information will help us understand what secondary school is like for students. It will also help teachers to understand students and how they act and behave in secondary school.

If you have any questions for me, I can be contacted by phone or email.

Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813

Supervisors  Dr Olive Healy, olive.healy@tcd.ie, ph:8961175 and Dr Michael Gordon, gordonms@tcd.ie, ph 01 8962969, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2
Signing this paper means that you have read this or had it read to you and that you want to be in the study. If you don’t want to be in the study, don’t sign the paper. Remember, being in the study is up to you, and no one will be angry if you don’t sign this paper or even if you change your mind later.

Name of Student

Signature of student ____________________

Or

Email return check box ☐

Date

Statement of investigator’s responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed assent.

INVESTIGATORS SIGNATURE: (to be signed by Katie Cremin on return)

--------------------------------------------------------------

DATE
THE NISONGER CHILD BEHAVIOR RATING FORM

TEACHER VERSION: SCORE SHEET

Child's Name: ________________________________  Child's Date of Birth: ______/_____/______

Rater's Name: ________________________________  Date of Rating: ______/_____/______


INSTRUCTIONS. Transcribe the ratings from the Nisonger CBFR and write them into the 'rating' column next to the appropriate item number '##'. When all ratings have been transcribed, total the columns to obtain the subscale scores.

II. POSITIVE SOCIAL   III. PROBLEM BEHAVIOR

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<th></th>
<th>Compliant / Calm</th>
<th>Adaptive Social</th>
<th>Conduct Problem</th>
<th>Insecure / Anxious</th>
<th>Hyperactive</th>
<th>Self-Injurious / Stereotypic</th>
<th>Self-Isolated / Ritualistic</th>
<th>Irritable</th>
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</table>

THE NISONGER CHILD BEHAVIOR RATING FORM

TEACHER VERSION

Child's Name: ___________________________ Child's Date of Birth: ________________

Rater's Name: ___________________________ Date of Rating: ________________


(please specify)


How long have you had this child in your class? (check one) less than 3 months [1] 3 to 6 months [2] more than 6 months [3]

I. Please describe any special circumstances or mediating factors that may have affected the child's behavior in the recent past (the last month or two) or prevented you from making complete ratings.

II. POSITIVE SOCIAL. Please describe the child's behavior as it was in the classroom over the last month.

IN THE LAST MONTH, THIS CHILD HAS: Not Somewhat or Very or Completely or True Sometimes True Often True Always True

1. Accepted redirection 9 9
2. Expressed ideas clearly 1 1
3. Followed rules 2 2
4. Initiated positive interactions 3 3
5. Participated in group activities 4 4
6. Resisted provocation, was tolerant 5 5
7. Shared with or helped others 6 6
8. Stayed on task 7 7
9. Was cheerful or happy 8 8
10. Was patient, able to delay 9 9

Page 1 (OVER)
III. PROBLEM BEHAVIOR. For each item that describes the child's behavior as it was over the last month, circle the score that best describes the behavior.

0... if the behavior did not occur or was not a problem
1... if the behavior occurred occasionally or was a mild problem
2... if the behavior occurred quite often or was a moderate problem
3... if the behavior occurred a lot or was a severe problem

For each problem that occurred, circle only the score that best describes the behavior.

PLEASE DO NOT SKIP ANY QUESTIONS. IF YOU DO NOT KNOW THE ANSWER OR HAVE NOT HAD A CHANCE TO OBSERVE THE CHILD FOR A GIVEN TIME, CIRCLE THE ZERO.

| 1. Apathetic or unmotivated | 0 1 2 3 |
| 2. Argues with parents, teachers, or other adults | 0 1 2 3 |
| 3. Clings to adults, too dependent | 0 1 2 3 |
| 4. Cruelty or meanness to others | 0 1 2 3 |
| 5. Crying, tearful episodes | 0 1 2 3 |
| 6. Hits or slaps own head, neck, hands, or other body parts | 0 1 2 3 |
| 7. Defiant, challenges adult authority | 0 1 2 3 |
| 8. Knowingly destroys property | 0 1 2 3 |
| 9. Difficulty concentrating | 0 1 2 3 |
| 10. Disobedient | 0 1 2 3 |
| 11. Rocks body or head back and forth repetitively | 0 1 2 3 |
| 12. Doesn't feel guilty after misbehaving | 0 1 2 3 |
| 13. Easily distracted | 0 1 2 3 |
| 14. Easily frustrated | 0 1 2 3 |
| 15. Overly sensitive; feelings easily hurt | 0 1 2 3 |
| 16. Exaggerates abilities or achievements | 0 1 2 3 |
| 17. Explosive, easily angered | 0 1 2 3 |
| 18. Has rituals such as head rolling or floor pacing | 0 1 2 3 |
| 19. Fails to finish things he/she starts | 0 1 2 3 |
| 20. Feelings easily hurt | 0 1 2 3 |
| 21. Feels others are against him/her | 0 1 2 3 |
| 22. Harms self by scratching skin or pulling hair | 0 1 2 3 |
| 23. Feels worthless or inferior | 0 1 2 3 |
| 24. Fidgets, wiggles, or squirms | 0 1 2 3 |
| 25. Shy around others; bashful | 0 1 2 3 |
| 26. Gets in physical fights | 0 1 2 3 |
| 27. Irritable | 0 1 2 3 |
| 28. Repeatedly flaps or waves hands, fingers or objects (such as pieces of string) | 0 1 2 3 |
| 29. Isolates self from others | 0 1 2 3 |
| 30. Lying or cheating | 0 1 2 3 |
| 31. Nervous or tense | 0 1 2 3 |
| 32. Gouges self, puts things in ears, nose, etc., or eats inedible things | 0 1 2 3 |
| 33. Overactive, doesn't sit still | 0 1 2 3 |

34. Overly anxious to please others | 0 1 2 3 |
35. Overly excited, exuberant | 0 1 2 3 |
36. Physically attacks people | 0 1 2 3 |
37. Refuses to talk | 0 1 2 3 |
38. Repeats the same sound, word, or phrase over and over | 0 1 2 3 |
39. Restless, high energy level | 0 1 2 3 |
40. Runs away from adults, teachers, or other authority figures | 0 1 2 3 |
41. Says no one likes him/her | 0 1 2 3 |
42. Secretive, keeps things to self | 0 1 2 3 |
43. Repeatedly bites self hard enough to leave tooth marks or break skin | 0 1 2 3 |
44. Self-conscious or easily embarrassed | 0 1 2 3 |
45. Shifts rapidly from topic to topic when talking | 0 1 2 3 |
46. Short attention span | 0 1 2 3 |
47. Shy or timid behavior | 0 1 2 3 |
48. Steals | 0 1 2 3 |
49. Odd repetitive behaviors (e.g., stares, grimaces, rigid postures) | 0 1 2 3 |
50. Stubborn, has to do things own way | 0 1 2 3 |
51. Sudden changes in mood | 0 1 2 3 |
52. Sulk, silent and moody | 0 1 2 3 |
53. Physically harms or hurts self on purpose | 0 1 2 3 |
54. Talks back to teacher, parents, or other adults | 0 1 2 3 |
55. Talks too much or too loud | 0 1 2 3 |
56. Temper tantrums | 0 1 2 3 |
57. Threatens people | 0 1 2 3 |
58. Threatens to harm self | 0 1 2 3 |
59. Engages in meaningless, repetitive body movements | 0 1 2 3 |
60. Too fearful or anxious | 0 1 2 3 |
61. Underactive, slow | 0 1 2 3 |
62. Unhappy or sad | 0 1 2 3 |
63. Violates rules | 0 1 2 3 |
64. Withdrawn, uninvolved with others | 0 1 2 3 |
65. Worrying | 0 1 2 3 |
66. Argues with other children or peers | 0 1 2 3 |

PAGE 2
Parent Questionnaire - Autistic Spectrum Disorder / Autism and Secondary School Experience

These questions are about your child, their abilities, their Autism or ASD and their schooling.

Please only answer if you are the parent of a student in secondary school with a diagnosis of Autism / ASD living in the Republic of Ireland.

Any queries or questions contact Katie Cremin: cremink@tcd.ie or 0878161845

1. **Geographic area**
   - Mark only one oval.
   - rural
   - urban

2. **Your child's date of birth**

3. **Gender of your child**
   - Mark only one oval.
   - Male
   - Female

4. **Your child's age at diagnosis**

5. **Any co-occurring diagnosis?**
   - Check all that apply.
   - Seizure disorder
   - Intellectual disability
   - Gastro - intestinal
   - Sleep disorder
   - Developmental co-ordination disorder
   - Anxiety
   - ADHD
   - Other:
6. Do you have a recent psychological assessment for your child?
   If yes - can you provide some detail such as level of intellectual ability or IQ?

7. How well can your child carry out a conversation?
   Please choose one option
   Mark only one oval.
   - with no trouble
   - with a little trouble
   - with a lot of trouble
   - he/she has no conversational ability

8. How often would your child join in group activities without being told?
   Please choose one option
   Mark only one oval.
   - never
   - sometimes
   - very often
   - don't know

9. Would your child make friends easily?
   Please choose one option
   Mark only one oval.
   - never
   - sometimes
   - very often
   - don’t know

10. How often would your child seem confident in social situations/parties or groups?
    Please choose one option
    Mark only one oval.
    - never
    - sometimes
    - very often
    - don’t know
11. Can your child dress him or herself completely?
   please choose one option
   Mark only one oval.
   □ very well
   □ pretty well
   □ not very well
   □ not well at all
   □ don't know

12. How well can your child tell the time on a clock with hands?
   please choose one option
   Mark only one oval.
   □ very well
   □ pretty well
   □ not very well
   □ not at all well
   □ don't know

13. How well can your child read and understand common signs, like STOP, MEN, WOMEN, or DANGER?
   please choose one option
   Mark only one oval.
   □ very well
   □ pretty well
   □ not very well
   □ not at all well
   □ don't know

14. How well can your child get to places outside the home, like to a nearby shops or park, or to a neighbors house?
   please choose one option
   Mark only one oval.
   □ very well
   □ pretty well
   □ not very well
   □ not at all well
   □ don't know
15. How would you describe your child's schooling?
   Mark only one oval.
   - full time mainstream secondary school
   - part time / shorter hours mainstream secondary school
   - full time special class or unit in a secondary school
   - part time mainstream and part time special unit or class in a secondary school
   Other: _______________________________________

16. Does your child spend any part of the day in
   Mark only one oval.
   - special / resource classroom
   - one to one teaching
   - non-academic intervention e.g. social skills
   Other: _______________________________________

17. Does your child have an SNA
   Mark only one oval.
   - yes - full time
   - yes - part time
   - no
   Other: _______________________________________

18. Does your child have an IEP (Individualised Educational Plan)
   Mark only one oval.
   - yes
   - no
   Other: _______________________________________

19. Is school transport / bus provided for your child?
   Mark only one oval.
   - yes
   - no
   - other

20. Has your child ever missed secondary school for a period longer than two weeks?
    please provide details below
    _______________________________________
    _______________________________________
    _______________________________________
    _______________________________________
    _______________________________________
21. Has your child experienced different school placements since they entered secondary school?  
please provide details below

22. Has your child ever had a behaviour support plan tailored to their individual needs?  
please provide details below

23. Does your child participate in extracurricular activities in the school setting?  
please provide details below

24. Does your child participate in extracurricular activities outside of the school setting?  
please provide details below

25. How has your child settled in secondary school  
Mark only one oval.

- very easily
- somewhat easily
- somewhat challenging
- very challenging
26. How well would you say your child gets along with other students at the school?
Mark only one oval.
- very well
- pretty well
- not very well
- not at all well

27. How well would you say your child gets along with teachers at the school?
Mark only one oval.
- very well
- pretty well
- not very well
- not at all well

28. Think about your child’s experience at secondary school this year. How would you agree with the following statements.
Mark only one oval per row.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know</th>
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<tr>
<td>School is challenging</td>
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<td>He / she enjoys school</td>
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<td>There is an adult at the school who knows him/her and cares about him / her</td>
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<td>The school is good at meeting his / her individual needs</td>
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<td>He / she is getting the support services from the school the he / she needs to do well in school</td>
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</table>

29. Does your child attend a service for children with ASD
Check all that apply.
- yes
- no

30. Do they receive support in secondary school from this service? (if yes to previous question)
Check all that apply.
- yes
- no

31. These questions have been included as a measure of ASD in children and youth.
Please answer each question by clicking yes or no. A few questions ask about several related types of behavior: Please tick yes if any of these behaviors 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.
Mark only one oval per row.

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<tr>
<th></th>
<th>yes</th>
<th>no</th>
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<td>12.</td>
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</table>
13. 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)?

14. Has she/he ever seemed to be unusually interested in the sight, feel, sound, taste, or smell of things or people?

15. 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?

16. Has she/he ever had any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?

17. Has she/he ever injured her/himself deliberately, such as by biting her/his arm or banging her/his head?

18. Has she/he ever had any objects (other than a soft toy or comfort blanket) that she/he had to carry around?

19. Does she/he have any particular friends or a best friend?

20. When she/he was 4 to 5, did she/he ever talk with you just to be friendly (rather than to get something)?

21. 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)?

22. When she/he was 4 to 5, did she/he ever spontaneously point at things around her/him just to show you things (not because she/he wanted them)?

23. 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?

24. When she/he was 4 to 5, did she/he not her/his head to mean...
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes/No Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. When she/he was 4 to 5, did she/he shake her/his head to mean no?</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>26. When she/he was 4 to 5, did she/he usually look at you directly in</td>
<td>Yes/No Options</td>
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<tr>
<td>the face when doing things with you or talking with you?</td>
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<tr>
<td>27. When she/he was 4 to 5, did she/he smile back if someone</td>
<td>Yes/No Options</td>
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<tr>
<td>smiled at her/him?</td>
<td></td>
</tr>
<tr>
<td>28. When she/he was 4 to 5, did she/he ever show you things that</td>
<td>Yes/No Options</td>
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<td>interested her/him to engage your attention?</td>
<td></td>
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<tr>
<td>29. When she/he was 4 to 5, did she/he ever offer to share things</td>
<td>Yes/No Options</td>
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<tr>
<td>other than food with you?</td>
<td></td>
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<tr>
<td>30. When she/he was 4 to 5, did she/he ever seem to want you to join</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>in her/his enjoyment of something?</td>
<td></td>
</tr>
<tr>
<td>31. When she/he was 4 to 5, did she/he ever try to comfort you if you</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>were sad or hurt?</td>
<td></td>
</tr>
<tr>
<td>32. When she/he was 4 to 5, when she/he wanted something or wanted</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>help, did she/he look at you and use gestures with sounds or words to</td>
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<tr>
<td>get your attention?</td>
<td></td>
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<tr>
<td>33. When she/he was 4 to 5, did she/he show a normal range of facial</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>expressions?</td>
<td></td>
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<tr>
<td>34. When she/he was 4 to 5, did she/he ever spontaneously join in and</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>try to copy the actions in social games, such as The Mulberry Bush or</td>
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<tr>
<td>London Bridge is Falling Down?</td>
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<tr>
<td>35. When she/he was 4 to 5, did she/he play any pretend or make-believe games?</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>36. When she/he was 4 to 5, did she/he seem interested in other</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>children of approximately the same age whom she/he did not know?</td>
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</tr>
<tr>
<td>37. When she/he was 4 to 5, did she/he respond positively when another child approached her/him?</td>
<td>Yes/No Options</td>
</tr>
<tr>
<td>38. 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?</td>
<td>Yes/No Options</td>
</tr>
</tbody>
</table>
| 39. 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?

40. 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?

33. I would like to send your son / daughter's teacher a questionnaire in relation to social competence and behaviour in school. Please provide contact details of your chosen teacher / school personnel to whom I can send this questionnaire and details of the study. Alternatively please include your own contact details if you would like to give the documents to the teacher yourself

please complete contact details below. (please include your child's name so as I can identify them to the school)

34. The follow up to this study will look at engagement and satisfaction with the secondary school experience. Please provide your contact details below if you would like to be contacted in relation to this phase of the study.

please complete contact details below.

35. Please provide an e-mail address (if you have one or not already given above), so that I can contact you in relation to this study. *note: contact details will be stored separately to questionnaires in order to retain anonymity.

Consent
36. I consent to taking part in this research project. I understand that agreeing to take part means that I am willing to: 1. Complete the Social Communication Questionnaires about my child. 2. Provide information about my child and their school. 3. Give permission for my child's teacher to be contacted to complete a questionnaire about my child. 4. Give my contact details. 5. Allow the information gathered to be used anonymously in the research project which may be published in a journal or at a conference. 6. Be contacted in the future if my information is wanted for further research. I understand that no personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted files on password protected computers. If I wish to access my information at any stage, it will be made available to me. I have the right to access my personal data at any time under the Freedom of Information Act (1997). The information I provide will be stored at Trinity College Dublin for a period of 10 years. I may request access to my information at any time of the study or at any point during the 10 year period. If information emerges that raises a serious concern for the safety or well-being of any individual, the researcher will be required to report this through the appropriate channels. I understand that there is a risk that I could become upset by the issues raised during the research project and the researchers will provide support or find the relevant support for me in this instance. I understand that I can withdraw from the study if I want to. I may also request any data pertaining to me or my child be removed from the study prior to the point of analysis and submission of the research report or publication (i.e. September 2016).

Please fill your name if you consent to take part in the research project.
Experience of Secondary School Study

This is a study about students with Autistic Spectrum Disorder (ASD) experience of secondary school. Your participation is voluntary; all data will be anonymous and is confidential.

Teacher Questionnaire

Please answer the questions by ticking the appropriate box or filling in the correct information

About your school:
Approximately how many students attend your school? ___________
Approximately how many teachers work in the school? ___________
Approximately how many support teaching staff work in the school? ___________
Approximately how many students with Special educational needs attend the school? ___________
Approximately how many students with ASD attend the school? ___________
About your teaching experience and ASD:

How many years teaching experience do you have? ____________________

How many years experience with students with ASD do you have? __________

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<tr>
<td>I am knowledgeable about ASD.</td>
<td></td>
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<tr>
<td>I have taken a course that covered ASD.</td>
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<tr>
<td>I have attended training day or a workshop on ASD.</td>
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<td>I have read a substantial amount about ASD.</td>
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<td>I have researched the internet regarding ASD.</td>
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<td>I have worked extensively with individuals with ASD.</td>
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<tr>
<td>I am familiar with applied behaviour analysis and behaviour modification procedures.</td>
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<tr>
<td>I frequently use behavioural teaching strategies.</td>
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<tr>
<td>I have taken a course in applied behaviour analysis or behaviour modification.</td>
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<tr>
<td>I have attended training day or a workshop on applied behaviour analysis or behaviour modification.</td>
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<tr>
<td>I have read a substantial amount on applied behaviour analysis or behaviour modification.</td>
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<tr>
<td>I am a professional who specializes in applied behaviour analysis or behaviour modification.</td>
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</table>
About the student with ASD:
The questionnaire overleaf is in relation to the named student with ASD. Please complete it to the best of your knowledge.

Please indicate this student’s typical schooling and class type:

i) Full time mainstream secondary school ☐
ii) Part time / shorter hours mainstream secondary school ☐
iii) Full time special class or unit in a secondary school ☐
iv) Part time mainstream and part time special unit or class in a secondary school ☐
v) Other ☐ __________________________

vi) Does the student spend any part of the day in special / resource classroom ☐
i) Does the student spend any part of the day in one on one ☐
ii) Does the student spend any part of the day in non-academic intervention e.g., social skills ☐

iii) Does the student have an SNA?
yes ☐ no ☐ full-time ☐ part-time ☐

iv) Does the student have an IEP (Individualised Educational Plan)?
yes ☐ no ☐

v) Any additional information about class / teaching arrangements
_____________________________________________________
_____________________________________________________
Appendix C: Letters, Consent and Participant Information, questionnaire and measures - Study 3 and 4
The ALLY Project

A school based educational programme to improve links between students with and without Autistic Spectrum Disorder (ASD)

What is the project about and what is its purpose?
The ALLY project stands for Autism and creating Lasting Links in Youth. An ally is a person who associates or cooperates with another or a supporter. To ally means to combine or unite resources with others for a shared benefit. This project is about increasing school wide knowledge and improving attitudes towards students with Autism Spectrum Disorder (ASD). It aims to increase interaction behaviours of transition year students towards their peers with ASD who attend special classes or units within the secondary school campus. It also aims to raise understanding amongst transition year students of initiatives and adaptations, which could improve the wellbeing and communications of pupils attending ASD classes or units. This project is part of a PhD looking at the secondary school experience for students with ASD, which is being completed in the Children’s Research Centre, Trinity College Dublin (TCD) and supervised in the School of Psychology, TCD.

What is involved?
As the parent of a student in transition year in secondary school, you and your child are being asked to give your consent and their assent to participating or being a comparison in the project and measuring its outcomes. The project will involve six class length sessions with transition year students on the following topics:

1. Understanding Autism
2. Attitudes and Behaviour
3. Being an Ally
4. Sensory processing
5. Ally to Ally
6. Prompting and Reinforcing during Interactions
There will also be some interactive sessions where students with and without ASD can share learning activities and group social activities. Measures of knowledge, attitude, intentions of behaviour towards those with ASD and understanding the behaviour of those with ASD will be taken before and after the project. These will be pencil and paper standardised questionnaires and completed in school. The questionnaires will be completed anonymously and coded. There will be some anonymous observations taken during the interactive sessions. A final copy of the research report will be made available to you if you wish to receive it.

**Confidentiality**

No personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the project. All information will be stored in locked filing cabinet or as encrypted files on password-protected computers. If you wish to access your child’s information at any stage, it will be made available to you. You have the right to access their personal data at any time under the Freedom of Information Act (1997). Please also note that if information emerges that raises a serious concern for the safety or wellbeing of any individual, the researcher will be required to report this through the appropriate channels.

**Voluntary participation and withdrawal**

If you decide to consent to your child participating in the ALLY Project, you may withdraw them at any time without consequence; you may also request any data pertaining to your child be removed from the project prior to the analysis of data in December 2016. If you would like your child to participate in the project but not complete the measures this is also acceptable.

**What are the benefits of taking part?**

The ALLY Project is aiming to add to the limited knowledge base around participation in secondary school for students with ASD in Ireland. It is hoped that it will explore the current context for students with ASD and highlight areas for improvement in terms of school initiatives and integration. It is also anticipated that participating students will improve their knowledge, attitude and behaviours towards students with ASD.

**What are the risks or disadvantages of taking part?**
The risks associated with participating in this project are minimal. If your child finds any aspect stressful or difficult, you or they can discuss it with the researcher and are free to withdraw from the project at any point. Information in relation to support can be made available to you and them also.

**Ethical Permission**

This research project has research ethics committee approval from the School of Psychology, Trinity College Dublin.

**Further Information**

You can get more information including copies of the questionnaires / measures or answers to further questions about the project, participation in the project, and your child’s rights from Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813 or her supervisor Dr Olive Healy, olive.healy@tcd.ie, ph:8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2.

If the project team learns of any important new information that might affect your child’s desire to remain in the project, you and they will be informed at once.
The ALLY Project - A school based educational programme to improve links between students with and without Autistic Spectrum Disorder (ASD)

Thank you for your participation in this project. This project has been designed to increase school wide knowledge and improving attitudes towards students with Autism Spectrum Disorder (ASD). To increase interaction behaviours of transition year students towards their peers with ASD who attend special classes or units within the secondary school campus. It also aims to raise understanding amongst staff and transition year students of initiatives and adaptations, which could improve the wellbeing and communications of pupils attending ASD classes or units. The information from your questionnaires and measures will be analysed to look the outcomes of the project.

If you decide that you would not like this information to be used in this study, please let me know, your data can be removed prior to the point of analysis and submission of the research report or publication (i.e., December 2016).

In the event that you feel a need to speak to a professional concerning any uncomfortable or stressful feelings arising from your participation in this study, please contact; Dr Olive Healy, olive.healy@tcd.ie, ph:8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2.

Irish Autism Action also has a counselling service, you can contact them at counselling@autismireland.ie or call 044 9371680

If you are interested in learning more about this research study, or finding out the results of the study, please do not hesitate to contact:

Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, or her supervisor; Dr Olive Healy, olive.healy@tcd.ie, ph:8961175 School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2
The ALLY Project

*A school based educational programme to improve links between students with and without Autistic Spectrum Disorder (ASD)*

**What is the project about and what is its purpose?**

The ALLY project stands for Autism and creating Lasting Links in Youth. *An ally is a person who associates or cooperates with another or a supporter. To ally means to combine or unite resources with others for a shared benefit.*

This project is about increasing school wide knowledge and improving attitudes towards students with Autism Spectrum Disorder (ASD). It aims to increase interaction behaviours of transition year students towards their peers with ASD who attend special classes or units within the secondary school campus. It also aims to raise understanding amongst transition year students of initiatives and adaptations, which could improve the wellbeing and communications of pupils attending ASD classes or units.

This project is part of a PhD looking at the secondary school experience for students with ASD, which is being completed in the Children’s Research Centre, Trinity College Dublin (TCD) and supervised in the School of Psychology, TCD.

**What is involved?**

As the parent of a student who attends an ASD class or unit in secondary school, you and your child are being asked to give your consent and their assent to participating in the project and measuring its outcomes.

Your child is invited to participate in three interactive sessions where students with and without ASD can share learning activities and group social activities.

The transition year students will also participate in sessions designed to improve knowledge and understanding of Autism on the following topics:

1. Understanding Autism
2. Attitudes and Behaviour
3. Being an Ally
4. Sensory processing
5. Interaction and communication
6. Prompting and Reinforcing during Interactions
Parents of students with ASD are also being asked to complete a questionnaire about your child’s social competence and behaviour in school - called the Nisonger Child Behaviour Rating form *, a Social Communication Questionnaire and a questionnaire related to school experience. All measures will be sent to you via the school along with stamped addressed envelopes (SAE) for their return. These measures should take no longer than 30 to 40 minutes to complete.

*In the event that this measure comes up strongly with serious self injurious behaviours or behaviours of serious concern to the student, family or teachers well being – A protocol will be put in place to offer advice in seeking assistance for these behaviours

A final copy of the research report will be made available to you if you wish to receive it.

Confidentiality
No personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the project. All information will be stored in locked filing cabinet or as encrypted files on password-protected computers. If you wish to access your child’s information at any stage, it will be made available to you. You have the right to access their personal data at any time under the Freedom of Information Act (1997). Please also note that if information emerges that raises a serious concern for the safety or wellbeing of any individual, the researcher will be required to report this through the appropriate channels.

Voluntary participation and withdrawal
If you decide to consent to your child participating in the ALLY Project, they may withdraw or you may withdraw them at any time without consequence; you may also request any data pertaining to your child be removed from the project prior to the analysis of data in December 2016.

If you would like your child to participate in the project but not complete the measures this is also acceptable.

What are the benefits of taking part?
The ALLY Project is aiming to add to the limited knowledge base around participation in secondary school for students with ASD in Ireland. It is hoped that it will explore the current context for students with ASD and highlight areas for improvement in terms of
school initiatives and integration. It is also anticipated that participating students will improve their knowledge, attitude and behaviours towards students with ASD.

**What are the risks or disadvantages of taking part?**

The risks associated with participating in this project are minimal. If your child finds any aspect stressful or difficult, you or they can discuss it with the researcher and are free to withdraw from the project at any point. Information in relation to support can be made available to you and them also.

**Ethical Permission**

This research project has research ethics committee approval from the School of Psychology, Trinity College Dublin.

**Further Information**

You can get more information including copies of the questionnaires / measures or answers to further questions about the project, participation in the project, and your child’s rights from Ms Katie Cremin, cremink@tcd.ie, ph. 01 8963813 or her supervisor Dr Olive Healy, olive.healy@tcd.ie, ph: 01 8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

If the project team learns of any important new information that might affect your child’s desire to remain in the project, you and they will be informed at once.

---

**Thank you for your help and participation.**
The ALLY Project

*An ally is a person who associates or cooperates with another or a supporter. To ally means to combine or unite resources with others for a shared benefit.*

My name is Katie Cremin, I work and study at Trinity College Dublin.

The ALLY Project is happening at your school.

I would like to invite you to be part of The ALLY Project.

This project is about meeting 4th year students in your school.

- You can meet them at lunch time.
- You can also do a project with them.
- You can have a fun time with them.

Your teachers and parents will also be part of the project. They will tell me more about you. They will tell me about your school. I will also come in and meet you.

I hope you would like to be part of the ALLY project.

If you have any questions for me, I can be contacted by phone or email. Katie Cremin, *cremink@tcd.ie*, ph 0878161845

or

My supervisor: Dr Olive Healy, *olive.healy@tcd.ie*, ph:8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

Signing this paper means that you have read this or had it read to you and that you want to be in the project. If you don’t want to be in the project, don’t sign the paper. Remember, being in the project is up to you, and no one will be angry if you don’t sign this paper or even if you change your mind later.

Name of Student ______________________

Signature of student ___________________
Statement of investigator’s responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed assent.

INVESTIGATORS SIGNATURE: (to be signed by Katie Cremin on return)

---------------------------------------------------------------

DATE
The ALLY Project

Autism and Lasting Links for Youth

An ally is a person who associates or cooperates with another or a supporter. To ally means to combine or unite resources with others for a shared benefit.

My name is Katie Cremin, I work and study at Trinity College Dublin. I would like to invite you to be part of The ALLY Project. This project is designed for transition year students to learn more about those with Autistic Spectrum Disorder. It will also help you interact and socialise more with students with ASD in your school who attend special classes or units, and hopefully help you understand why they sometimes behave differently.

For transition year students there are six classes, which you are invited to attend. The topics are as follows:

1. Understanding Autism
2. Attitudes and Behaviour
3. Being an Ally
4. Sensory processing
5. Ally to Ally
6. Prompting and Reinforcing during Interactions
There will also be some extra interactive sessions were students with and without ASD can share a learning activities and group social activities.

Measures of your knowledge, attitude, intentions of behaviour towards those with ASD and understanding the behaviour of those with ASD will be taken before and after the project. These will be pencil and paper standardised questionnaires and you will complete them in school before and after the project classes and sessions. You do not have to put your name on the questionnaire.

If your group is a comparison group you will complete these questionnaires twice and have class as normal.
A large number of students are being asked to be part of this study. All this information will help us understand what secondary school is like for students with ASD. For students without ASD it’s hoped that you will understand ASD more and be able to interact more easily with students with ASD and be their ally.
If you have any questions for me, I can be contacted by phone or email.

Ms Katie Cremin, cremink@tcd.ie, ph 0878161845
Supervisor: Dr Olive Healy, olive.healy@tcd.ie, ph:8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

Signing this paper means that you have read this or had it read to you and that you want to be in the study. If you don’t want to be in the study, don’t sign the paper. Remember, being in the study is up to you, and no one will be angry if you don’t sign this paper or even if you change your mind later.

Name of Student ______________________

Signature of student ______________________

Date ______________________

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed assent.

INVESTIGATORS SIGNATURE: (to be signed by Katie Cremin on return)

----------------------------------------------------------------------------------------------------------------------------------

DATE
Parent/guardian

Study title: The ALLY Project

A school based educational programme to improve links between students with and without Autistic Spectrum Disorder (ASD)

Contact details: Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

Academic supervisors: Dr Olive Healy, olive.healy@tcd.ie, ph:8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

I have read and understood the information leaflet. I consent to taking part in this research project. I understand that agreeing to take part means that I am willing to:

- Complete the Social Communication Questionnaires about my child
- Complete the Nisonger Child Behaviour Rating form
- Complete the School Participation section of the PEM – CY
- Provide some demographic information about my child and their school experience.
- Allow the information gathered to be used in the research project which may be published in a journal or at a conference.
- Give permission for my child to participate in three shared sessions with transition year students
- Be contacted in the future if my information is wanted for further research.

I understand that no personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted files on password protected computers. If I wish to access my information at any stage, it will be made available to me. I have the right to access my personal data at any time under the Freedom of Information Act (1997). The information I provide will be stored
at Trinity College Dublin for a period of 10 years. I may request access to my information at any time of the study or at any point during the 10 year period.

If information emerges that raises a serious concern for the safety or well-being of any individual, the researcher will be required to report this through the appropriate channels.

I understand that there is a risk that I could become upset by the issues raised during the research project and the researchers will provide support or find the relevant support for me in this instance.

I understand that I can withdraw from the study if I want to. I may also request any data pertaining to me or my child be removed from the study prior to the point of analysis and submission of the research report or publication (i.e., December 2016).

DECLARATION:
I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Please fill in the following if you consent to take part in the research project:

PARTICIPANT'S NAME
(print):........................................................................................

PARTICIPANT'S SIGNATURE:...................................................
Date:.................................

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR’S SIGNATURES..............................................
Date:.............

Ms Katie Cremin, cremink@tcd.ie, ph 01 8963813, or her supervisors Dr Olive Healy, olive.healy@tcd.ie, ph:8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2
Parent/guardian of transition year student

Study title: The ALLY Project

A school based educational programme to improve links between students with and without Autistic Spectrum Disorder (ASD)

Contact details: Ms Katie Cremin, cremink@tcd.ie, ph. 01 8963813, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

Academic supervisors: Dr Olive Healy, olive.healy@tcd.ie, ph: 8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2

I have read and understood the information leaflet. I consent to my son / daughter in transison year taking part in this research project. I understand that agreeing to take part means that I am consenting to them:

- Participating in six educational sessions relating to ASD and strategies for interaction.
- Participating in three interactive sessions were students with and without ASD can share learning activities and group social activities, anonymous observations will be taken during these sessions.
- Completing measures of knowledge, attitude, behavioural intention and attribution of behaviour. * (before and after project) * (if they are in a comparison group this will be a three time points).
- Allow the information gathered to be used in the research project, which may be published in a journal or at a conference.
- Be contacted in the future if my information is wanted for further research.

I understand that no personally identifiable information will be included in the research reports. Personally identifiable information will not be published or disclosed to anyone outside the study. All information will be stored in locked filing cabinet or as encrypted
files on password-protected computers. If I wish to access my child’s information at any stage, it will be made available to me. I have the right to access their personal data at any time under the Freedom of Information Act (1997). The information they provide will be stored at Trinity College Dublin for a period of 10 years. I may request access to my information at any time of the study or at any point during the 10-year period. If information emerges that raises a serious concern for the safety or well being of any individual, the researcher will be required to report this through the appropriate channels.

I understand that there is a risk that they could become upset by the issues raised during the research project and the researchers will provide support or find the relevant support for them in this instance.

I understand that they can withdraw from the study if they want to. I may also request any data pertaining to my child or me be removed from the study prior to the point of analysis and submission of the research report or publication (i.e., December 2016).

DECLARATION:
I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Please fill in the following if you consent to take part in the research project:

PARTICIPANT'S NAME
(print):.................................................................................................

PARTICIPANT'S SIGNATURE:.................................................................
Date:........................................

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved.
I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR’S SIGNATURES...........................................................

Date:..............

Ms Katie Cremin, cremink@tcd.ie, ph. 01 8963813, or her supervisors Dr Olive Healy, olive.healy@tcd.ie, ph: 8961175, School of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2
STUDENT MEASURES

Knowledge of Autism Questionnaire

Have you any previous experience with someone with autism?
Yes_____ No_______

We would like to know what you know about autism. Please answer the following questions using true or false. If you believe the statement is true, please circle T. If you believe the statement is false, please circle F. Even if you are not sure of the answer, please answer all the questions as best you can.

1. If someone has autism, it only lasts for about a week. T  F
2. Students with autism often have a difficult time looking at other people. T  F
3. Autism does not affect a person’s brain. T  F
4. Students with autism cannot do normal activities that other people can do, even with help from another person. T  F
5. Students with autism sometimes repeat what is said to them. T  F
6. Students with autism sometimes rock back and forth and wave their hands around. T  F
7. Some students with autism might have trouble talking or expressing themselves. T  F
8. Students with autism do not have difficulty changing activities and can easily move from one activity to another. T  F
9. Sometimes students with autism need extra help to learn how to read and write. T  F
10. You can catch autism by spending time with someone who has it, like you can catch a cold. T  F
SAQ

Sam does not talk or play with the other students; he finds it hard to make friends. When Sam speaks its usually the same word over and over again. For example he might say “My name is Sam. My Name is Sam. My name is Sam.” It is hard to know how Sam is feeling, like if he is happy, sad or angry. He spends a lot of time on his own, sometimes rocking back and forth on a chair. He has a silver ball that he brings everywhere, he likes to hold and watch the ball.

If Sam moves to your school and is in your class, here is a list of things you might do with him. Circle the emoji face to answer how you might feel about doing things with Sam.

😊 = yes  😐 = maybe  🙁 = no

1. Ask Sam to come to my house and watch TV.
😊  😐  🙁

2. Sit next to Sam in class.
😊  😐  🙁

3. Work in the school library / shop with Sam.
😊  😐  🙁

4. Share my games or books with Sam.
😊  😐  🙁
5. Work on a science project at school with Sam. 😊😊😊

6. Be in the same extra reading group with Sam. 😊😊😊

7. Study history topics with Sam at school. 😊😊😊

8. Invite Sam to my birthday party or get together. 😊😊😊

9. Ask Sam to go into town with me. 😊😊😊

10. Go on a day out with Sam and his family. 😊😊😊

11. Eat lunch next to Sam in school. 😊😊😊

12. Walk together with Sam in the hall at school.
13. Do art with Sam in class.

14. Go to Spar / Centra shop with Sam.

15. Work on Maths problems in class with Sam.

16. Write a project or report for school with Sam.

17. Ask Sam to join a club I’m in.

18. Do homework with Sam at home after school.

19. Go to the cinema with Sam.

20. Hangout with Sam outside during lunch break.
21. Pick Sam to be my partner in sports with other students.

22. Be good friends with Sam.

23. Go to watch a sports match / game with Sam.

24. Go to McDonald’s with Sam

Thank you
Please answer as honestly as you can. There are no ‘right’ answers.

1= Strongly Disagree
2=Disagree
3=Agree
4=Strongly agree

Circle the number which matches your answer.

1. People with autism should not engage in romantic relationships.

   1  2  3  4

2. People with autism should have the opportunity to go to college.

   1  2  3  4

3. People with autism should not have children

   1  2  3  4

4. People with autism should be institutionalised for their safety and others.

   1  2  3  4

5. If a facility to treat people with autism opened near my house, I would want to move away.
6. Individuals with autism are incapable of living on their own.
   1 2 3 4

7. I would be afraid to be around a person with autism.
   1 2 3 4

8. A person with autism is an emotional burden on his / her family.
   1 2 3 4

9. I would be comfortable sitting next to a person with autism in my class.
   1 2 3 4

10. A person with autism is a financial burden on his / her family.
    1 2 3 4

11. People with autism should be encourage to marry someone with autism
    1 2 3 4
12. People with autism are incapable of forming relationships and expressing affection.

1 2 3 4

13. Children with autism should be fully integrated into mainstream classes

1 2 3 4

14. I would be uncomfortable hugging a person with autism.

1 2 3 4

15. People with autism cannot understand other people’s feelings.

1 2 3 4

16. Students with autism who are mainstreamed into regular classrooms are a distraction to students without autism in that classroom.

1 2 3 4
1. Are you aware of what the term Neurodiversity means?
   If yes, where did you learn about it?
   a) No, I am not aware of it
   b) Yes, I heard of it online
   c) Yes, I read about it in a book/magazine
   d) Yes, I heard about it in person
   e) Yes, I heard about it at a club, society or extra curricular activity
   f) Yes, I heard about it at an event outside school
   g) Yes, but at none of the above

2. What do you think Neurodiversity is in your own words?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

3. How do you (think you would) feel about being on the autism spectrum / having autism? (Please tick as many choices as you like)

<table>
<thead>
<tr>
<th>Happy</th>
<th>Bored</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overwhelmed</td>
<td>Confused</td>
</tr>
<tr>
<td>Sad</td>
<td>Ashamed</td>
</tr>
<tr>
<td>Proud</td>
<td>Excited</td>
</tr>
<tr>
<td>Frustrated</td>
<td>Other</td>
</tr>
<tr>
<td>Angry</td>
<td>Don’t know</td>
</tr>
<tr>
<td>Content</td>
<td></td>
</tr>
<tr>
<td>Indifferent</td>
<td></td>
</tr>
</tbody>
</table>

4. Do you agree or disagree with parents of children on the autism spectrum should:
   a) Seek a cure for their child?   Agree □ Disagree □
   b) Teach their child how to develop adaptive skills (i.e., look after themselves: dressing, eating and personal hygiene)?   Agree □ Disagree □
   c) Teach their child how to appear more like a typically developing person?   Agree □ Disagree □
   d) Understand that autism is part of their child’s identity?   Agree □ Disagree □
   e) Try to learn why their child is on the autism spectrum?   Agree □ Disagree □
f) Learn to speak their child’s language (i.e., use sign language, pictures or adaptive technology on tablets/ipads)?

Agree □ Disagree □

5. What do you think is the cause of autism?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Quiz about Project Ally

Please tick one answer for each question......✓

1) Autism affects
   a. 1 in 10 people □
   b. Only children □
   c. 1 in 100 people □
   d. I don’t know □

2) Autism is considered a spectrum because
   a. There are many types of autism diagnosis □
   b. There are different degrees of severity or difficulty in autism □
   c. Autism affects social abilities □
   d. I don’t know □

3) Having autism in secondary school can impact majorly on
   a. Reading □
   b. Maths □
   c. Inclusion □
   d. I don’t know □

4) Communication with students with autism can be reinforced using
   a. A loud voice □
   b. sign language □
c. visual schedule □

d. I don't know □

5) Proprioception refers to
   a. what we see □
   b. our body awareness □
   c. our sense of touch □
   d. I don’t know □

6) An sensory friendly space is
   a. full of friendly people □
   b. not too distracting □
   c. very tidy □
   d. I don't know □

7) A reinforcement should be
   a. not obvious □
   b. strong and consistent □
   c. immediate and specific □
   d. I don't know □

8) A prompt can be
   a. Physical, verbal or gestural □
   b. Distracting during a task □
   c. A shared learning activity □
   d. I don't know □
PROJECT ALLY FEEDBACK

- Do you like going to school?
  😊=yes    😕=maybe    ☹️=no

- Do you have friends at school?
  😊=yes    😕=maybe    ☹️=no

- Do you like this Project ALLY class?
  😊=yes    😕=maybe    ☹️=no

- Did you learn new things in this class?
  😊=yes    😕=maybe    ☹️=no

- Did you like working with the 4+ years in this class?
  😊=yes    😕=maybe    ☹️=no

- Did working with the 4+ years help you learn new things?
  😊=yes    😕=maybe    ☹️=no

- Did you make new friends?
  😊=yes    😕=maybe    ☹️=no

- Would you like to keep working with the 4+ years?
  😊=yes    😕=maybe    ☹️=no
PROJECT ALLY FEEDBACK B

😊=yes (I agree) 🙁=maybe (I’m not sure) ☹️=no (I don't agree)

Students in the class benefited socially from the project?
😊=yes 🙁=maybe ☹️=no

I benefited socially from the project?
😊=yes 🙁=maybe ☹️=no

Overall I enjoyed participating in this project?
😊=yes 🙁=maybe ☹️=no

The amount of time required was reasonable?
😊=yes 🙁=maybe ☹️=no

I would need on-going support to keep up what I learnt?
😊=yes 🙁=maybe ☹️=no

Students in have more friends / allies because of this project?
😊=yes 🙁=maybe ☹️=no

I could use things I learnt in this project with other people?
😊=yes 🙁=maybe ☹️=no

I feel I was effective as a participant?
😊=yes 🙁=maybe ☹️=no

I took part with enthusiasm?
The project was a good way to include the students from

I felt confident during the project?

I felt I had enough help and support to be part of this project?

The project was too much work for me?

I feel I was effective in this project?

The information sessions were useful?

Other 4th year students should do this?
I would do a project like this again?

😊=yes  😐=maybe  😞=no

I understand why 4+ year students are better for this project than teachers / adults?

😊=yes  😐=maybe  😞=no

I would consider the students in my allies / friends?

😊=yes  😐=maybe  😞=no

I would recommend this project to others?

😊=yes  😐=maybe  😞=no

My views about students with autism have changed?

😊=yes  😐=maybe  😞=no

My views about people who are neuro-diverse have changed?

😊=yes  😐=maybe  😞=no
Appendix D: Project ALLY Material and Photos
Project Ally
Autism and Lasting Links for Youth

An ally is a person who associates or cooperates with another or a supporter.
To ally means to combine or unite resources with others for a shared benefit.

Outline of sessions

1. Understanding Autism
2. Our Attitudes and Behaviour
3. Being an Ally
4. What is Sensory processing
5. Ally to Ally
6. Prompting and Reinforcing Interactions

Shared Activities

1  
2  
3  

Session 1
What is Autism?

• Autism is a diagnosis which affects up to 1 in 100 people all over the world.

• Autism is known as a spectrum as people will have traits or characteristics which are identified with autism. These can be of varying degrees of severity or difficulty.

• The common traits of autism are identified in the following areas:
  - Social skills
  - Communication skills
  - Behaviour
  - Sensory Processing

Neurodiversity

• Neurodiversity recognises differences in the way our brains work.

• Neurodiversity is a concept that allows society to accept differences in the way people think, instead of trying to change or cure them.

• Autism is considered as neurodiverse.

• People without neurodiversity are often referred to as neurotypical.

• Neuro – brain

• Diverse – different
Quotes about Autism - discussion

“If you’ve met one person with autism, you’ve met one person with autism,” Dr. Stephen Shore.

“And now I know it is perfectly natural for me not to look at someone when I talk. Those of us with Autism are just not comfortable doing it. In fact, I don’t really understand why it’s considered normal to stare at someone’s eyeballs,” John Elder Robison.

“The most interesting people you’ll find are ones that don’t fit into your average cardboard box. They’ll make what they need, they’ll make their own boxes,” Dr. Temple Grandin.

“For autistic individuals to succeed in this world, they need to find their strengths and the people that will help them get to their hopes and dreams. In order to do so, ability to make and keep friends is a must. Amongst those friends, there must be mentors to show them the way. A supportive environment where they can learn from their mistakes is what we as a society needs to create for them,” Bill Wong, Autistic Occupational Therapist.
“Although people with autism look like other people physically, we are in fact very different. We are more like travelers from the distant, distant past. And if, by our being here, we could help the people of the world remember what truly matters for the Earth, that might give us quiet pleasure.”

Naoki Higashida, The Reason I Jump

“English is my 2nd language. Autism is my first,”

Dani Bowman

“My autism makes things shine. Sometimes I think it is amazing but sometimes it is sad when I want to be the same and talk the same and fail. Playing the piano makes me very happy. Playing Beethoven is like your feelings—all of them—exploding.”

Mikey Allcock, 16-year-old who was nonverbal until age 10

Handout

- The spectrum PDF
- Group brainstorm/reflection
Session 2

How to be a good ALLY

- An ally is a person who associates or cooperates with another or a supporter.
- To ally means to combine or unite resources with others for a shared benefit.
- Appreciating individual difference and similarities.
- Brainstorm similarities and differences

Case examples

Dylan – apple guy

ATTITUDE

QUESTIONS
- Where do you think he will go after high school?
- Do you think he has or will have a girl/boyfriend?
- Where will he live as an adult?
- How would you be if Dylan sat next to you in class?
- Do you think he was fully integrated in his school?
- Do you think he has many friends?
- Do you think he was ever bullied?
- Do you think he was a distraction to others in school?
- What do you think his main strengths are?
- What do you think his main challenges are?
Shared activities 🤗

QUESTIONS – If Dylan was in your year would you……..
- Invite him to hang out with you after school?
- Like to work with him in a pair on a maths project?
- Choose to sit next to him at lunch?
- Invite him to the cinema?
- Work on an art project with him in a group?

Being Autistic in Secondary school 🎓😊

- Challenges

- Positives

Being Autistic in Secondary School – What the research tells us..........

- Stressful – the environment especially noise and chaos.
- Value friendships – especially for group activity such as sport.
- Bullying is common.
- Homework is a challenge – handwriting.
- Teachers who are too strict or difficult to understand.
- Know they are ‘different’ but want to be included.

Session 3
Being an Ally

• Organising free time - break times e.g. sport, game, music etc.
• Sharing – offering to share space, information, time, belongings etc.
• Providing assistance – offering help or just recognising what might be helpful (Prompting)
• Providing affection and praise – high fives, ‘that’s brilliant’, ‘great to see you’ etc. (Reinforcement)

Focus on Communication

• How do students communicate?
• How do students interact with the environment and learn?
• Neurotypical and neurodiverse
• http://www.autism.ie/about-autism/communication

Visuals

• Visual instructions can be helpful for people with Autism. We ALL know how important visual instructions can be as we all need them in certain situations.
• Clear visual instructions for tasks, activities and navigation are really useful.
Session 4

Sensory Processing

- Our seven senses
  - Taste
  - Smell
  - Vision
  - Hearing
  - Proprioception or body awareness
  - Vestibular or movement sense
  - Tactile or Touch

Sensory Friendly Spaces

- Are less noisy
- Tolerate movement and fidgeting
- Less bright
- Not too many distractions
- Allow choice
- Have structure / predictable
- Patience and tolerance
Sensory Friendly Lunch hour

- Challenges
- Planning

Session 5

Ally to Ally

- Reciprocity i.e. two sided
- On the level
- Lack of structure is difficult
- Anxiety about social situations
- Model social interaction
- Imagination
- Context clues
- Celebrate strengths

Ideas

- Basketball with ally who loves numbers, but not keen on sport.
- Lunch break chat with ally who doesn't initiate conversation.
- Explain the rules of a board game to an ally who wants to play it during break.

Session 6

Prompting & Reinforcing Interactions

- Interaction is a two way process.
- Initiating interaction is hard.
- We need to be able to interpret non verbal communication.
- We can boost interaction through practice and encouragement.
- Practicing interactions might mean slowing down interactions and using guidance or prompting.
- It's important to acknowledge all interactions, this is reinforcing - e.g. smile, laugh, nod etc.

Prompting

- Gesture
- Verbal (e.g., clues, hints, commands, questions, rule or statement)
- Visual (e.g., pictures, objects)
- Model (full, partial)
- Physical (full, partial)

Reinforcement

- Positive reinforcement
- Specific to behaviour
- Specific to student
- Immediate
- Ignore negative behaviour or redirect
Project ALLY – tips for Autism friendly verbal communication

1. **Be specific and direct**

   e.g., ‘put the cup on the table’ instead of “put it here”

   Pronouns are tricky – e.g., he, she, you, it, this, that
   *So use the name or noun

   Prepositions are tricky – e.g., in, on, under
   *So you can point

   Time concepts are tricky - e.g., soon, later, yesterday
   *So you can be more accurate “in five minutes” or use timers

   Quantity words are tricky – e.g., some, more, lots
   *so you can be more accurate

   Burger ------ big mac
   Boy ----------- Jack
   Movie -------- Toy Story 3
   Chocolate ------- Galaxy Bar

   Avoid expressions or sayings
   e.g., Cough it up or It’s raining cats and dogs

2. **Give plenty of time to process**

   - It might take someone up to 30 seconds to ‘process’ what you’ve said so hold tight and be patient.
- Make sure you have the person's attention when you start to speak
- Use visual prompts and pointing
- Use pauses, silences and be as clear as possible.
- Emphasise the command e.g., open the book

3. Be positive – not harsh
   - redirect the situation
   - change the activity
   - praise

4. Don't use too many questions and give choices if you do.
   e.g., “let’s start reading page three” instead of “are you ready to start?”
   e.g., “Do you want crackers or bread?” instead of “what do you want for lunch

5. Use first then sentences
   “first a chat about our hobbies then we go outside for break” instead of “we are going to go outside after we have a quick chat”
Joint Session 1
- Intro groups of 2/3 students

Group game
- take a coin each
- take a logo sign per group
- where is coin from?
- what year is on the coin?
- something that happened to you in the year on the coin?
- What is the logo?
- Do you have a story that connects a member of your group to the logo?
- One person in each group tells the story (not the person who it is about)
**Project ALLY**

**Treasure Hunt**

- Form teams 3 or 4 people.
- One person can write answers.
- One person can take the pictures
- One person can collect items
- Work as a team.
- Decide on a team name.
- Follow the instructions on the treasure hunt sheet
- You have 20 minutes for this treasure hunt.
- There is a time penalty if you are not back within 20 minutes
- It is not a race the team with the most points will win
- Team with best name also gets a prize
- DO NOT Run
- DO NOT make a loud noise
Treasure Hunt

TEAM NAME:

**Bring back the following items**
1. Something you can eat (10 points)
2. An adult’s signature (15 points)
3. A tissue (5 points)
4. Something red (5 points)
5. Something blue (5 points)
6. 1 cent (10 points)

**Photograph the following on ipad**
7. A cardboard box (5 points)
8. A teacher (20 points)
9. Your team under a tree (10 points)
10. The Home Economics room door number (5 points)
11. The special in the canteen (10 points)
12. Something Grey (5 points)

**Write down an interesting fact about each member of your group (40 points)**
13.
14.
15.
16.
1) Make teams of 3 or 4 people
2) The aim of the task is to build the tallest construction you can out of the cocktail sticks and jellies
3) You can use as much of the cocktail sticks and jellies as you need
4) Work as a team
5) You have 15 minutes to complete the task

Tips
- Eiffel tower or spire shapes work well.
- Planning is very important.
- Triangles are stronger than squares
- Make things strong - use trusses, or framing

**Ask** - What? Ask questions, understand the need, identify the problem, define
• What is the problem to solve? How will we know when we solved the problem?
• What is already known?
• Are there guidelines for what we can or can't do?

Imagine - So what? Imagine, brainstorm, explore, discover

• What are some other ideas for solutions to similar problems? * examples of towers and tall buildings, trusses, triangle - Pinterest board * tallest buildings and structures in the world - Wikipedia
• How is this problem different from the examples?
• Which ideas might work for solving this problem?

Design, Build - Plan, Create, Experiment - Now what? Plan, design. Do it. Create, try it out

• What are some ideas to include in the design?
• What does the best possible solution look like?
• Make a prototype, and test it.
• Does the prototype look like to plan? Does it still meet the requirements?

Improve - If this then what? Improve, make it better

• Is this a good solution to the problem? Could it be better? How could this be improved?
• How were each of the 4Cs - creativity, critical thinking, collaboration, communication - used during the project?
• How does the Engineering Design Process help?

That's engineering

• triangles are stronger than squares
• make things strong - use trusses, or framing
• calculate the forces on a free-standing triangle or square, and prove that shapes other than triangles are statically indeterminate.
• for a static system, all the forces must balance out: The sum of all forces acting on the system must be zero. Which also means that: 1) the sum of the horizontal components of the forces equals zero 2) the sum of the vertical components of the forces equals zero
Project ALLY
Certificate of Completion
awarded to

Date:

Signed: [Signature]
Assistant Professor in Occupational Therapy

An ally is a person who associates or cooperates with another or a supporter.

To ally means to combine or unite resources with others for a shared benefit.
Enthusiasm  Help  Neurodiversity's  Interacting
Fun  Bowling  Trip  Appreciation
Helping  Friends  Better
Social  Highs  Happy
Conversation  4th
Appendix E: American Academy of Neurology Classification of Evidence
American Academy of Neurology Classification of Evidence

Therapeutic

Class I: A randomized, controlled clinical trial of the intervention of interest with masked or objective outcome assessment, in a representative population. Relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences.

The following are also required:
   a. concealed allocation
   b. primary outcome(s) clearly defined
   c. exclusion/inclusion criteria clearly defined
   d. adequate accounting for drop-outs (with at least 80% of enrolled subjects completing the study) and cross-overs with numbers sufficiently low to have minimal potential for bias.
   e. For non inferiority or equivalence trials claiming to prove efficacy for one or both drugs, the following are also required* 
      1. The authors explicitly state the clinically meaningful difference to be excluded by defining the threshold for equivalence or non-inferiority.
      2. The standard treatment used in the study is substantially similar to that used in previous studies establishing efficacy of the standard treatment. (e.g., for a drug, the mode of administration, dose and dosage adjustments are similar to those previously shown to be effective).
      3. The inclusion and exclusion criteria for patient selection and the outcomes of patients on the standard treatment are comparable to those of previous studies establishing efficacy of the standard treatment.
      4. The interpretation of the results of the study is based upon a per protocol analysis that takes into account dropouts or crossovers.

Class II: A randomized controlled clinical trial of the intervention of interest in a representative population with masked or objective outcome assessment that lacks one criteria a-e above or a prospective matched cohort study with masked or objective outcome assessment in a representative population that meets b-e above. Relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences.

Class III: All other controlled trials (including well-defined natural history controls or patients serving as own controls) in a representative population, where outcome is independently assessed, or independently derived by objective outcome measurement.**

Class IV: Studies not meeting Class I, II or III criteria including consensus or expert opinion.

* Note that numbers 1-3 in Class Ie are required for Class II in equivalence trials. If any one of the three are missing, the class is automatically downgraded to Class III.
**Objective outcome measurement:** an outcome measure that is unlikely to be affected by an observer’s (patient, treating physician, investigator) expectation or bias (e.g., blood tests, administrative outcome data).

**Diagnostic**

**Class I:** A cohort study with prospective data collection of a broad spectrum of persons with the suspected condition, using an acceptable reference standard for case definition. The diagnostic test is objective or performed and interpreted without knowledge of the patient’s clinical status. Study results allow calculation of measures of diagnostic accuracy.

**Class II:** A case control study of a broad spectrum of persons with the condition established by an acceptable reference standard compared to a broad spectrum of controls or a cohort study where a broad spectrum of persons with the suspected condition where the data was collected retrospectively. The diagnostic test is objective or performed and interpreted without knowledge of disease status. Study results allow calculation of measures of diagnostic accuracy.

**Class III:** A case control study or cohort study where either persons with the condition or controls are of a narrow spectrum. The condition is established by an acceptable reference standard. The reference standard and diagnostic test are objective or performed and interpreted by different observers. Study results allow calculation of measures of diagnostic accuracy.

**Class IV:** Studies not meeting Class I, II or III criteria including consensus, expert opinion or a case report.

**Prognostic**

**Class I:** A cohort study of a broad spectrum of persons at risk for developing the outcome (e.g., target disease, work status). The outcome is defined by an acceptable reference standard for case definition. The outcome is objective or measured by an observer who is masked to the presence of the risk factor. Study results allow calculation of measures of prognostic accuracy.

**Class II:** A case control study of a broad spectrum of persons with the condition compared to a broad spectrum of controls or a cohort study of a broad spectrum of persons at risk for the outcome (e.g., target disease, work status) where the data was collected retrospectively. The outcome is defined by an acceptable reference standard for case definition. The outcome is objective or measured by an observer who is masked to the presence of the risk factor. Study results allow calculation of measures of prognostic accuracy.

**Class III:** A case control study or a cohort study where either the persons with the condition or the controls are of a narrow spectrum where the data was collected retrospectively. The outcome is defined by an acceptable reference standard for case definition. The outcome is objective or measured by an observer who did not determine
the presence of the risk factor. Study results allow calculation of measures of a prognostic accuracy.

**Class IV:** Studies not meeting Class I, II or III criteria including consensus, expert opinion or a case report.

**Screening**

**Class I:** A statistical, population-based sample of patients studied at a uniform point in time (usually early) during the course of the condition. All patients undergo the intervention of interest. The outcome, if not objective, is determined in an evaluation that is masked to the patients’ clinical presentations.

**Class II:** A statistical, non-referral-clinic-based sample of patients studied at a uniform point in time (usually early) during the course of the condition. Most patients undergo the intervention of interest. The outcome, if not objective, is determined in an evaluation that is masked to the patients’ clinical presentations.

**Class III:** A sample of patients studied during the course of the condition. Some patients undergo the intervention of interest. The outcome, if not objective, is determined in an evaluation by someone other than the treating physician.

**Class IV:** Studies not meeting Class I, II or III criteria including consensus, expert opinion or a case report.

**Causation**

**Class I:** Prospective cohort study design that satisfies these criteria— (a) groups studied are representative of population of interest (‘broad spectrum’); (b) risk factors and outcomes are clearly defined with validated or generally accepted criteria, and measured independently or objectively; (c) comparison groups are matched for known possible confounding risk factors, or the effects of such confounders are controlled in the study analysis; AND (d) measures of association are expressed (or can be calculated) as rate ratios, risk ratios, relative risks (R.R.) or population attributable risks with confidence intervals.

**Class II:** Retrospective cohort or case-control study designs that satisfy criteria (a), (b), and (c) above, in which (d) the measure of association may also be expressed (or can be calculated) as an odds ratio (O.R.) with confidence intervals.

**Class III:** Other cohort or case-control study designs in which groups studied represent a narrow spectrum of the population of interest, or the measure of association does not include an R.R. or O.R. but does include an aggregate measure such as a correlation or group mean with standard deviation or p-value. Criterion (b) above must still be satisfied. Obvious confounding is not evident.

**Class IV:** Studies not meeting criteria for Class I, II, or III. Specifically, studies that are non-comparative, unrepresentative of the population of interest, with major biases or
confounding, lacking useful measures of effect, or lacking measures of effect estimate stability.

Notes:
1. In addition to the criteria above, any causal inference requires that exposure to the risk factor precede the development of the outcome. In addition, there may be need to allow for an induction period.
2. In translating evidence, a requirement of two or more studies implies that such studies should not include the same subjects.
3. Exploratory studies involving multiple comparisons of a variety of exposures and outcomes may be rated lower if it is evident that the study was designed without an a priori hypothesis or focus upon the specific exposure and outcome of interest.
4. Randomized clinical trials (RCTs) are equivalent to prospective cohort studies in which the risk of confounding has been minimized. Evidence from such studies may be considered Class I, provided it satisfies criteria (a), (b), and (d) above. Note, however, that it is preferable to apply the AAN criteria for therapeutic studies when classifying evidence pertaining to the experimental (treatment) variables of an RCT.

Classification of Recommendations

A = Established as effective, ineffective or harmful (or established as useful/predictive or not useful/predictive) for the given condition in the specified population. (Level A rating requires at least two consistent Class I studies.)*

B = Probably effective, ineffective or harmful (or probably useful/predictive or not useful/predictive) for the given condition in the specified population. (Level B rating requires at least one Class I study or two consistent Class II studies.)

C = Possibly effective, ineffective or harmful (or possibly useful/predictive or not useful/predictive) for the given condition in the specified population. (Level C rating requires at least one Class II study or two consistent Class III studies.)

U = Data inadequate or conflicting; given current knowledge, treatment (test, predictor) is unproven.

*In exceptional cases, one convincing Class I study may suffice for an “A” recommendation if 1) all criteria are met, 2) the magnitude of effect is large (relative rate improved outcome > 5 and the lower limit of the confidence interval is > 2).

Classification of Recommendations (causation)

A = Risk factor is a highly probable contributor to the development of disease or outcome. (Level A rating requires two or more consistent Class I studies all showing an effect size (R.R.) ≥2 with lower confidence limits >1. In addition, either (1) a causal inference is coherent with known biologic mechanisms and related scientific evidence or (2) findings clearly demonstrate that higher doses of exposure increase likelihood of disease or outcome.)
B = Risk factor is a probable contributor to the development of disease or outcome. (Level B rating requires at least one Class I study fulfilling other criteria above, OR two or more consistent Class II studies, showing an effect size (R.R. or O.R.) ≥1.5 with lower confidence limits >1.)

C = Risk factor is a possible contributor to the development of disease or outcome. (Level C rating requires 1 Class II or 2 or more Class III studies, showing effect estimate(s) with consistent significant departure(s) from null value.)

U = A causal relationship between the risk factor and disease or outcome is unproven or unsupported.