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Life skills provision in the UK for young people with Autism Spectrum Disorders: An investigation of the views and needs of parents, young people and education providers.

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A thesis submitted in partial fulfilment of the requirements of the University of Kent and the University of Greenwich for the Degree of Doctor of Philosophy.

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DECLARATION

I certify that this work has not been accepted in substance for any degree and is not concurrently being submitted for any degree other than that of Doctor of Philosophy being studied at the universities of Kent and Greenwich. I also declare that this work is the result of my own investigations except where otherwise identified by references and that I have not plagiarised the work of others.

Sofia Chantziara --

Dr. Alison Bratt --

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ABSTRACT

The aim of the thesis was to investigate life skills provision for high functioning young people with ASDs and to contribute to the development of future school-based interventions. A mixed methods design including two qualitative and one quantitative study was employed. Semi-structured interviews were conducted with young people with ASDs and their parents to obtain their views and experiences in relation to life skill training they have received, their aspirations for adulthood and needs for future training. Interviews were followed by focus groups with education providers to explore their views with regards to life skills training they offer and their recommendations for improvements. Findings from these two studies provided the basis for the design of two questionnaires aiming to further investigate and compare the views and experiences among parents and education providers. Parents and young people expressed a strong need for individualization of life skills support. Parents voiced a request for mentoring/befriending while young people asked for assistance with peer-relationships. There were also signs of parental conflict regarding their involvement in the support. Schools appeared to be corresponding to this need for individualization. They exerted great efforts to meet the specific needs of their pupils, and tried to incorporate life skills training into daily activities. However, support was applied in an informal, impromptu way, at the expense of more structured and effective programs. Furthermore, the involvement of neurotypical peers and parents in the support encountered obstacles, thus limiting the opportunities for generalization of the learned skills. Improving co-operation between schools and parents could be the first step in advancing school provisions. Emphasis should be placed on individualized support while also making use of evidence-based practices. Schools could also provide more hands-on support with peer-relationships and make use of “natural” opportunities available for practising life skills. Future interventions, should further investigate the involvement of neurotypical peers in life skills training and the effectiveness and applicability of mentoring /befriending, particularly within a school setting. The role of parents in the support should also be negotiated in each case as they may not always perceive their involvement as desirable or beneficial.

CONTENTS

FIGURES AND TABLES

LIST OF ABBREVIATIONS WITH EXPANSION

ABC	Aberrant Behaviour Checklist
ADIS-C	Anxiety Disorder Interview Schedule for Children
ADIS-C/P	Anxiety Disorder Interview Schedule for Children/Parents
ADOS	Autism Diagnostic Observation Schedule
AFAAS	Advancing Futures for Adults with Autism
AMAS-C	Adult Manifest Anxiety Scale-College Version
AQ	Autism Spectrum Quotidien
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
ASDS	Asperger Syndrome Diagnostic Scale
BASC-2	Behavioural Assessment System for Children-Second Edition
BDI	Beck Depression Inventory
BDI-II	Beck Depression Inventory-II
BDI-III	Beck Depression Inventory-III
BDI-Y	Beck Depression Inventory –Youth
BHS	Beck Hopelessness Scale
BRIEF	Behaviour Rating Inventory of Executive Function
CASI-Anx	Child and Adolescent Symptom Inventory-Anxiety Scale
CASI-20	Child and Adolescent Symptom Inventory-20
CBCL	Child Behaviour Checklist
CDI	Child Depression Inventory
CDI-2	Child Depression Inventory-Second Edition
CAMHS	Child and Adolescence Mental Health Service
CEF	Consultant Evaluation Form
CGB	Checklist for Group Behaviour
CGI-I	Clinical Global Impressions-Improvement scale
CSCY	Coping Scale for Children and Youth
DANVA-2	The Diagnostic Analysis of Non-Verbal Accuracy-2
DANVA-2-CF	The Diagnostic Analysis of Non-Verbal Accuracy-2 Child Facial Expressions
DASS	Depression Anxiety Stress Scale
DCL	Diagnostic Checklist for Pervasive Developmental Disorders

DD-CGAS	Developmental Disabled Children’s Global Assessment Scale
DfE	Department of Education
DSM	Diagnostic and Statistical Manual for Mental Disorders
EDI	Emory Dyssemia Index
EHC plan	Education, Health and Care plan
EHWA-VABS	Korean Version of the Vineland Adaptive Behaviour Scale
ERICA	Emotion Regulation Index for Children and Adolescents
ERQ	Emotion Regulation Questionnaire
EQ	Empathy Quotient
FaBeL	Family Burden Questionnaire
FEG	Questionnaire for the assessment of group behaviour
FQS	Friendship Quality Scale
GAS	Global Assessment of Functioning Scale
GMS	Global Mood Scale
GARS	The Gillian Autism Rating Scale
GARS-3	The Gillian Autism Rating Scale-3
IDEA	Individuals with Disabilities Education Act
IPR	Index of Peer Relationships
IRP-15	Intervention Rating Profile
K-CBCL	Korean Version of the Child Behaviour Checklist
K-10	Kessler-10
K-SSRS	Korean Version of Social Skills Rating System
MASC	Multidimensional Anxiety Scale for Children
NAS	National Autistic Society
N-CBRF	Nisonger Child Behaviour Rating Form
NEPSY-II	Neuropsychological Assessment-Second Edition
ODEP	Office for Disability Employment Policy
OFSTED	Office for Standards in Education
PANAS-C	Positive and Negative Affect Schedule for Children
PANAS-C-P	Positive and Negative Affect Schedule for Children-Parent Version
PARS	Paediatric Anxiety Rating Scale
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PedsQL	Paediatric Quality of Life Scale

PHCSCS-2	Piers-Harris Children’s Self-Concept Scale-Second Edition
PHS-2	Piers-Harris Self Concept Scale 2nd Edition
PHQ-9	Patient Health Questionnaire-9
PIA-CV mini	Parent Interview for Autism (shortened)
PRCA-24	Personal Report of Communication Apprehension
PSHE	Personal Social and Health Education
QOL	Quality of Life Questionnaire
QSQ	Quality of Socialization Questionnaire
QPQ	Quality of Play Questionnaire
RRQ	Rumination Reflection Questionnaire
RSES	Rosenberg Self-esteem Scale
SAS	Social Anxiety Scale
SBS	Sexual Behaviour Scale
SCAM	Situational Communication Apprehension Measure
SCARED	Screen for Child Anxiety Related Disorders
SCAS-C	Spence Children’s Anxiety Scale-Child Version
SCAS-P	Spence Children’s Anxiety Scale-Parent Version
SCI	Social Competence Inventory
SCL-90-R	Symptom Checklist-90-Revised
SCQ	Social Communication Questionnaire
SCPQ-P	Social Competence with Peers Questionnaire–Parents
SCPQ-PU	Social Competence with Peers Questionnaire-Pupils
SDQ	Strengths and Difficulties Questionnaire
SELSA	Social and Emotional Loneliness Scale for Adults
SEN	Special Education Needs
SENCO	Special Education Needs Coordinator
SIAS	Social Interaction Anxiety Scale
SKS	Social Competence Scale
SMCS	Social Motivation and Competencies Scale
SPCC	Self-Perceived Communication Competence Scale
SPS	Social Provision Scale
SRS	Social Responsiveness Scale
SRS-2	Social Responsiveness Scale-2

SSI	Social Skills Inventory
SSIS	Social Skills Improvement System
SSIS-RS	Social Skills Improvement System Rating Scales
SSRS	Social Skills Rating System
SSS	Stress Survey Schedule
SSQ-P	Social Skills Questionnaire-Parents
SSQ-PU	Social Skills Questionnaire-Pupils
STAI	State-Trait Anxiety Inventory
STAIC-S	State and Trait Anxiety Inventory for Children-State Subscale
STAIC-T	State and Trait Anxiety Inventory for Children-Trait Subscale
SWQ	Social Worries Questionnaire
TA	Teaching Assistant
TASSK	Test of Adolescent Social Skills Knowledge
TASSK-R	Test of Adolescent Social Skills Knowledge-Revised
TYASSK	Test of Young Adult Social Skills Knowledge
TOPS-3	The Test of Problem Solving-3
VABS	Vineland Adaptive Behaviour Scale
VDMI-R	Vocational Decision- Making Interview-Revised
WHO	World Health Organization

Chapter 1 : Introduction

1.1 Chapter summary

Life skills are considered essential for independent life and related deficits have been associated with negative outcomes in adulthood. However, acquiring these skills is a challenging process for individuals with ASDs, including those without co-occurring intellectual disability. It is being recommended that interventions which target life skills should start at school as there are limited services available after exiting educational provisions, especially for individuals without intellectual disability. Furthermore, the views and needs of those who receive and implement the interventions should be taken into consideration when designing and implementing new ones. Within this context the overall aims of the thesis are outlined along with the original contributions of the research, followed by a summary of each thesis chapter.

1.2 Symptomatology of ASDs

The term Autism Spectrum Disorders or ASDs is used as an umbrella term to refer to autism and all of the related disorders, including Asperger Syndrome (AS) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). ASDs are neurodevelopmental disorders, which are characterized by difficulties in social interaction, verbal and nonverbal communication and restrictive or repetitive patterns of thought or behaviours (Baron-Cohen, 2008; Boucher, 2008). ASDs can co-occur with different levels of cognitive ability. Some individuals will have profound intellectual impairment whilst others will be of average or above average intellectual ability. The term “high functioning”, although not a diagnostic category, is often used to describe those individuals with average or above average intelligence but who may struggle with issues related to social interaction and communication and exhibit repetitive and stereotyped patterns of behaviour. The official diagnostic criteria for ASD according to Diagnostic and Statistical Manual for Mental Disorders DSM-5 (2013) are the following:

“Autism Spectrum Disorder

Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, 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.

2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, 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.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, 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.

Specify current severity: Severity is based on social communication impairments and restricted repetitive patterns of behaviour. (See table below.)

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour. (See table below.)

Severity of autism spectrum disorders

Severity level	**Social communication**	**Restricted, repetitive behaviours**
Level 3 "Requiring very substantial support” Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.	Level 2 "Requiring substantial support” Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication. Inflexibility of behaviour, difficulty coping with change, or other restricted/repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.	Level 1 "Requiring support” Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-from conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful. Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:
-With or without accompanying intellectual impairment
-With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor
(Coding note: Use additional code to identify the associated medical or genetic condition.)
- Associated with another neurodevelopmental, mental, or behavioural disorder
(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioural disorder[s].)
- With catatonia"

Although all individuals with ASDs share the core symptoms (difficulties with social interaction and restricted, repetitive and stereotyped patterns of behaviour) their experiences can vary significantly as these symptoms can have very different manifestations. More specifically social difficulties could include: lack of interest in other people; atypical eye contact; preferring to be alone; not knowing how to react to another person's behaviour; difficulty reading emotional expressions; difficulty anticipating what someone may feel or think; difficulty accepting that there are multiple perspectives (Baron-Cohen, 2008).

Among the most common communication difficulties of individuals with ASDs one can identify: literal understanding of speech; using speech inappropriately for the social context; neologisms; echolalic speech; language delay. Repetitive or restrictive behaviours and patterns of thoughts can take the form of hand flapping; spinning the body; obsessional interests; highly repetitive behaviour; severe tantrums at change; unusual memory; need for sameness; very specific skills and areas of intelligence (Baron-Cohen, 2008).

All these difficulties become more challenging during adolescence, when there is an expectation to form peer relationships and be part of a social network (Mitchel, Regehr, Reaume, & Fieldman, 2010). Furthermore, they persist into adulthood and they can have a negative impact on several areas, such as employment, social life and independent living (Howlin, 2004).

1.3 Life skills and ASDs

The World Health Organization (WHO) describes life skills as “abilities for adaptive and positive behaviour that enable humans to deal effectively with the demands and challenges of everyday life” (WHO, 2004 p3). Life skills can be roughly grouped into three broad categories: 1) cognitive skills for analysing and using information; 2) personal skills for developing personal agency and managing oneself; 3) inter-personal skills for communicating and interacting effectively with others (WHO, 1999). Although life skills are innumerable and can also differ across various cultures, a core set of skills, consistently targeted through interventions, has been identified. These include: decision making; problem solving; creative thinking; critical thinking; effective communication; interpersonal relationship skills; self-awareness; empathy; coping with emotions and stress (WHO, 1999).

These psychosocial and interpersonal skills play an important role in the development of young people, from their earliest years into young adulthood (WHO, 1999) and they are important for independent life (Cronin, 1996). However, acquiring these skills is a challenging process for individuals with ASDs, including those without co-occurring intellectual disability. For the latter one’s research suggests that they tend to have poorer communication skills (Duncan & Bishop, 2015; Klin et al., 2007; Saulnier & Klin, 2005) and poorer social and daily living skills (e.g. caring for self; caring for home) (Duncan & Bishop, 2015; Klin et al., 2007; Liss et al., 2001; Saulnier & Klin, 2005) than would be expected based on their cognitive abilities.

1.4 Outcomes in adulthood for individuals with ASDs

Approximately 1.2% of the UK adult population, more than 1 in 100, have an ASD diagnosis (Brugha et al., 2012). The prevalence of diagnosed children aged 6–17 years is estimated at 2%, around 1 in 50, with school-aged boys being more than 4 times as likely as school-aged girls to have an ASD diagnosis (Blumberg et al., 2013).

Official UK figures show that 46% of people with disabilities are in employment (Office for Disability Issues, 2014). However, only 16% of adults with ASDs are in full time paid employment (NAS, 2016). According to US statistics, 20% of people with disabilities are in some form of employment (ODEP, 2016) and 90% of adults with ASDs are unemployed or underemployed (AFAA, 2016).

Longitudinal studies of individuals with ASDs and average to near average cognitive abilities also report adverse findings in the field of employment. A study by Howlin, Goode, Hutton, and Rutter (2004) of 68 individuals diagnosed with ASDs and with a non-verbal IQ of minimum 50 found that only one third of them were in some form of employment. Those with an IQ greater than 70 had slightly higher rates of employment than those with IQ of less than 70, while the majority of those jobs were in sheltered employment or voluntary in nature. A further study by Cederlund, Hagberg, Billstedt, Gillberg, and Gillberg (2008) showed that only 10% of participants with AS held ordinary jobs.

Most commonly reported difficulties experienced by individuals with ASDs are those associated with the social aspects of employment (e.g. acclimating to new job routines; communication; social interaction; ability to master the social demands of the workplace; social skills and executive functioning) but not with the actual job (Alverson, Lindstrom & Hirano 2015; Hurlbutt & Chalmers 2004).

In addition to employment, social life and interpersonal relationships can also be negatively affected as a young person with ASD matures. Young people with ASDs are highly concerned about their interpersonal relationships (Browning, Osborne, & Reed, 2009) while worries regarding dating and sexual relationships are also prominent (Cheak-Zamora, Teti & First, 2015). Longitudinal studies of individuals with average to near average cognitive abilities again reveal adverse findings. Farley et al. (2009) found that only 7% of their study's participants were married, 7% were in long term relationships and 44% had never dated. Similar findings were reported by

Engstrom, Ekstrom, and Emilsson (2003) who found that none of their sixteen participants were married, and by Howlin et al. (2004) who reported that 56% had no friends or acquaintances. This highlights the personal isolation that can often detrimentally impact the autistic adult.

Independent living also poses a number of challenges. All of the participants in a study by Farley et al. (2009) required continued help from parents or caregivers. Similar findings were reported by Howlin et al. (2004) where only 3 out of 68 individuals were living by themselves. According to Engstrom et al. (2003) even those individuals who were living in their own homes required support from public sector services and/or from family. In a study by Cederlund et al. (2008) although 73% of the participants were living independently all of them required support from parents.

However, it is worth noting that marked life skills deficits may not be the only causes of underachievement among individuals with ASDs. According to a social model of disability (Oliver, 2013) some of the difficulties could result from contextual and social factors such as discrimination, lack of environmental adaptation, or absence of continued employment supports.

Caregivers and young people with ASDs are concerned and feel anxious about transitioning to adulthood and inclusion becomes harder to achieve when school is left behind (Barnard, Prior, & Potter, 2000). Furthermore, there is a decline in the reliance and use of treatment services as children with ASDs grow older and finish their education (Gray et al., 2014).

1.5 **Support for young people with ASDs**

Differences exist between the US and the UK when it comes to provision of support to young people with ASDs, particularly within schools. However, some similarities are also present.

In the US some of the young people with an ASD diagnosis will also receive an Individualized Education Program (IEP). The IEP is a plan or program designed for pupils with Special Education Needs (SEN) to help them to get the most out of their education (Department of Education, 2000). The plan should set out targets and actions for the young person that are different from or additional to those that are in place for the rest of the class. The IEP is crucial as it determines reasonable learning goals and it establishes what services the school district will provide to the pupil.

Acquiring an IEP plan could be achieved by undergoing an assessment which will enable the young person to receive additional supports.

In the US the Individuals with Disabilities Education Act (IDEA) (IDEA, 2004) requires schools to plan for a pupil's transition to adulthood by the age 16, or earlier if the IEP team thinks it is appropriate. States can also set their own legislation in relation to transition (e.g. the state of Mississippi states that transition planning should start no later than the age of 14).

IEP goals and services should also help prepare pupils for adulthood. Services include a coordinated set of activities for a child with a disability that are designed to be within a results-oriented process; are focused on improving academic and functional achievement to facilitate movement from school; are based on the individual pupil's needs and other post-school adult living objectives. More specifically, transition planning includes preparation for employment; post-secondary education or training; independent living; involvement in the community.

In the UK, all educational establishments are expected to prepare their SEN pupils for adulthood (DfE,2015). These preparations focus on two main aspects. The first aspect addresses the requirements of higher education and employment. The second aspect refers to the need of supporting the development of a broader range of life skills, that will assist individuals to live independently, healthily, securely and also enable them to participate in society.

Some of the young people with an ASD diagnosis and with more complex educational needs will receive an Education, Health and Care (EHC) plan. This is a legal document identifying educational, health and social needs and outlining any additional support that is required to meet those needs (DfE & DHSC, 2015). Acquiring an EHC plan could be achieved by undergoing an assessment.

Although in the UK and the US pupils with ASDs can be entitled to additional support the UK legislation does not clearly defines a transition planning process. However, in theory, aspects of transition planning should be part of an EHC plan although no specific guidelines are provided. Education and Health are devolved matters in the UK and each of the devolved administrations is responsible for setting its own policies in this area. The legislation reported in the thesis mainly refers to England, however similar guidelines and recommendations have been adopted by the governments in Scotland, Wales and Northern Ireland (e.g. the autism strategy in

Scotland and Wales states that actions should be taken to improve education and employment outcomes) (House of Commons Library, 2019).

Young people with an ASD diagnosis in the UK can attend various educational placements including mainstream schools, specialist schools or schools and units specializing in ASDs. There are a number of factors that influence whether a young person attends any of the above placements such as availability, funding and preferences from local educational authorities (Jones, 2013). In most cases, specialist schools and units which specialize in ASDs will only accept pupils with an EHC plan. EHC plans are subject to assessments and not all pupils with ASDs will receive one. As a result, a number of pupils with an ASD diagnosis will not be entitled to formalized support, therefore limiting the responsibility of the schools to provide assistance.

1.6 School implementation of life skills interventions

School is considered a suitable place to implement interventions, as children of different socioeconomic backgrounds can be reached continuously over a long period (Anderssen, 2013). Research also indicates that there is a need to transfer successful interventions from controlled research environments into the classroom (Parsons et al., 2013) as in the UK and US most children and adolescents with ASDs attend regular or special education school settings. Indeed, the National Autistic Society (NAS) suggests providing life skills training in school to help young people when they leave educational provisions (Barnard et al., 2000). This may be particularly crucial for individuals with average intelligence, given the limited structures of support available to them after they leave school (Taylor & Seltzer, 2011).

Despite the evidence suggesting that life skills training at school would be beneficial, a review of school-based interventions for pupils with ASDs (Machalicek et al., 2008), showed that most of the interventions focusing on academic skills were directed at the age group 11-17 years. However, most of the interventions targeting communication, functional and social skills were directed at pupils below the age of 11. At the same time a number of studies showed that education providers may struggle to teach and support pupils with disabilities including those with ASDs (NAS, 2017; Jones, 2006; Gregor & Campbell, 2001). More to that, parents have also noted a lack of guidance regarding the transition from childhood to adulthood and inadequate support in schools (Portway & Johnson, 2005) and they also identified life skills training at schools among their main concerns (Barnard et al., 2000)

Both specialist and mainstream schools are expected to follow the same guidelines and support their pupils with ASDs while also preparing them for adulthood. However, studies have shown greater satisfaction levels among parents whose children attend specialist schools (Renty & Roeyers, 2005; Whittaker, 2007).

1.7 Social validation of life skills interventions

Young people with ASDs and their families share similar aspirations to others and identify competencies in social skills; self-care; emotional and behavioural maturity; friendships; relationships; educational opportunities and work among their desired outcomes (Beresford, Tozer, Rabiee, & Sloper, 2007; Barnard et al., 2000). Autistic adults, parents, and practitioners in the UK believe that research in ASDs should focus on issues of immediate practical concern and they prioritize everyday skills and employment (Pellicano, Dinsmore, & Charman, 2014). Taking into consideration the needs and views of individuals with ASDs, their families, and those of the practitioners during the design and implementation of interventions is of high importance.

Social validity refers to establishing the extent to which the goals, procedures, and outcomes of interventions are generally accepted by those who receive, implement, and oversee them (Lloyd & Heubusch,1996). Acceptability by the “consumers” is important in treatment selection and implementation as highly acceptable treatments are more likely to be adopted and applied (Gresham, Cook, Crews, & Kern, 2004).

According to Callahan, Henson, and Cowan (2008) in the area of ASDs there is a striking absence of social validity research. Little work has sought the views of the individuals and their families who should be consulted in the development of interventions and supports (Ratto & Mesibov, 2015). Individuals with ASDs have strong opinions about what could make a difference in their lives and these should be acknowledged (Hurlbutt & Chalmers, 2002).

1.8 Aims of the current research

In the area of ASD interventions, further research is required to identify effective strategies to promote independence in a holistic sense (Hendricks & Wehman, 2009) and to indicate the best ways to improve deficits in life skills that are often associated with negative outcomes (Gray et al., 2014). Within this context, the thesis had the following aims:

- Review and evaluate life skills interventions that are currently available for high functioning young people with ASDs.
- Explore the views and experiences of parents and young people with ASDs regarding life skills training and support they have received, with an emphasis on school provision, and their needs for future training.
- Investigate the views and experiences of education providers regarding the life skills training and support offered in their schools and their recommendations for improvements.
- Identify gaps in the current provisions and offer recommendations for research and practice.

1.9 Original Contributions

The thesis made several original contributions to knowledge:

- Identified shortcomings in the existing life skills interventions designed for high functioning young people with ASDs.
- Provided a picture of life skills provision for high functioning young people with ASDs in the UK.
- Investigated the experiences of young people with ASDs and their parents in relation to life skills training and support they had received.
- Directly consulted with both young people with ASDs and their parents about what types of interventions and supports would like to be made widely available.
- Explored life skills provision in schools.
- Gathered the views of education providers on the improvements they would like to see in the current system.

- Investigated and compared views and experiences in relations to life skills provision among parents whose children attend different types of school establishments and education providers who work in different type of school.
- Identified areas for improvement in school-based life skills provision.

1.10 Summary of chapters

The thesis includes seven chapters. Chapter 1 introduces the research while Chapters 2 and 3 present the literature review and the methodology respectively. Chapters 4, 5 and 6 outline the three studies of this thesis and Chapter 7 presents the final conclusions.

Chapter 2: Literature Review

Chapter 2 presents a systematic review of life skills interventions designed for high functioning young people with ASDs. The databases PubMed/ PsychInfo/ ERIC/ CINAHL were searched using a layered search strategy and 43 studies were identified. The Evaluative Method for Determining Evidence Based Practices-EBPs in Autism (Reichow, Volkmar &, Cicchetti, 2008) was applied to assess research report rigor and identify practices that have sufficient research evidence to be classified as EBPs.

Chapter 3: Methodology

Chapter 3 debates traditional research approaches and describes the rationale behind the choice of the mixed methods approach for the thesis. Benefits of this approach are outlined and the choice of a specific data collection method for each study is being discussed. Issues around validity and reliability within a qualitative research framework, along with ethical considerations are also addressed.

Chapter 4: Interviews

Chapter 4 describes a qualitative study aiming to investigate:

a) Views and needs in relation to adulthood as expressed by young people with ASDs and their parents.
b) Their experiences of previously accessed training and support, with an emphasis on school provision.
c) What type(s) of future life skills support they may consider beneficial and would wish to access.

Data were collected through semi-structured interviews with young people and their parents and were analysed using Thematic Analysis. Results and their implications for research and practice along with strengths and limitations of the study are discussed.

Chapter 5: Focus Groups

Chapter 5 describes a qualitative study aiming to investigate:

a) The types of life skills training that are being provided by the schools to pupils with ASDs.
b) Views of education providers regarding the current provisions.
c) Their recommendations for future improvements.

Data were collected through focus groups with education providers in mainstream and specialist schools and were analysed with Thematic Analysis. Results and their implications for research and practice along with strengths and limitations of the study are discussed.

Chapter 6: Cross-sectional survey

Chapter 6 describes the third study, aiming to investigate and compare the views and experiences of the parents whose children attend various types of school and the education providers who work at similar establishments, in relation to:

a) The life skills challenges that young people with ASDs experience.
b) The life skills training and support that is available to them.
c) Their types of support that they consider beneficial.

Data were collected through two anonymously administered questionnaires, each one designed exclusively for a specific group. The questionnaires reflected the findings from the two previous qualitative studies. Data from Likert- type scales, multiple choice, yes/no, ranking and open questions were analysed and specific hypotheses were tested. Results and their implications for research and practice along with strengths and limitations of the study are discussed.

Chapter 7: Conclusion and Summary

The final chapter summarizes overall findings and their implications for research and practice. Furthermore, the most significant limitations and strengths of the thesis are also presented and discussed. The chapter includes the evaluation of an event, which brought together parents, education providers and autism organizations. The aim of the event was to generate a discussion, promote communication and increase understanding around life skills provision.

1.11 Rationale for next chapter

Conducting a literature review was the first step in the research process. A review of life skills interventions that are available for high functioning young people with ASDs would help identify gaps in research and practice and establish the theoretical framework and methodological focus of the thesis.

Chapter 2 : Literature Review

2.1 Chapter summary

Background: Life skills can be defined as abilities for adaptive and positive behaviour and can include cognitive, personal and interpersonal skills. Deficits in life skills, which are prevalent even among high functioning individuals with ASDs, have been associated with negative outcomes in adulthood. More efforts are needed to identify effective strategies that can promote independence and improve life skills. The aim of this literature review was to identify and evaluate interventions designed to teach life skills for high functioning young people with ASDs.

Method: The databases PubMed/ PsychInfo/ ERIC/ CINAHL were searched using a layered search strategy. The Evaluative Method for Determining Evidence Based Practices (EBPs) in Autism was applied to assess research report rigor and identify practices that have sufficient research evidence to be classified as EBPs.

Results: 43 studies were identified and were divided into four categories based on the specific life skills their proposed interventions aimed to teach. The categories were: 1) Peer relationships; 2) Social skills; 3) Self-management skills; 4) Life planning skills. One EBP was identified and all interventions reported improvements in various areas of functioning. They also shared methodological shortcomings related to their applicability in school settings, limited evidence regarding long-term implementation and limited use of social validation procedures.

Conclusion: Interventions included in the current review focus on areas that individuals with ASDs, parents and practitioners have identified among their priorities. However, their various methodological shortcomings combined with the negative outcomes for adults with ASDs are indications that research in the area of life skills interventions should continue.

2.2 Introduction and aims of the review

Two literature reviews by Cappadocia and Weiss, 2011 and Palmen, Didden, and Lang, 2012 have previously provided an overview of interventions available for high functioning young people with ASDs. The former focused on group based social skills interventions while the latter included applied behavioural interventions aiming at improving adaptive skills.

Although they both found their included interventions to be promising, they also highlighted certain limitations, such as issues around generalization and maintenance of learned skills. The reviews suggested that there is a need for methodological rigor and controlled methodological designs. Both had a relatively narrow remit in terms of the interventions included and the life skills addressed.

The aim of this literature review was to investigate a wider field of research and to evaluate existing interventions designed to bolster life skills in a holistic sense for high functioning young people with ASDs. It can be difficult to specify exactly what constitutes a life skill. For that reason, the specification of what consists a life skill was based on the definition given by WHO in Chapter 1. More to that, broad search criteria were used to allow the identification of a range of interventions. Within this wide field of literature, the review had a more specific scope.

The review focused on interventions developed specifically for young people with ASDs as there is evidence that delivery for individuals with ASDs is more effective when it is specialized (Howlin, 2004). Interventions had to be delivered directly to the young people and those designed with the aim to offer training exclusively to parents fell outside of the scope of this review. The review aimed to capture interventions targeting transferrable skills that are relevant across different areas of functioning, rather than skills associated with a very specific task or skills that were applicable within a very specific context.

Furthermore, the focal point of the review was the content of life skills interventions instead of certain aspects of the delivered programs. In order to allow for a more comprehensive understanding of the interventions included in the review the section 2.3.3 Selection of studies describes in more detail which studies were excluded offering specific examples.

2.3 Method

2.3.1 Search strategy

The databases *PubMed/PsychINFO/ERIC/CINAHL* were searched using a layered search strategy. A combination of the keywords: Autism or ASD or Asperger or PDD AND Teen or Adolescent or Youth or Juvenile AND Program or Protocol or Train or Guideline or Intervene were used during an initial search. The precise search terms used are described in Appendix $A_{1.}$ The keywords were identified based on the language and terminology used in this subject area and through looking into background information to identify synonyms and other words commonly used. Initial familiarization with the literature in the area was crucial in choosing the keywords that were most commonly used and could facilitate the selection of relevant results (e.g. Pervasive Developmental Disorder is most commonly abbreviated to PDD; the terms youth, teen, adolescent were considered more appropriate than the term child which mainly refers to younger, primary school age children [Canaughton, Donovan, & March, 2017]). The keywords had to be present anywhere in the text.

A second search was completed using the same combination and adding the keywords Job or Work or Placement or Vocation. The aim of the second search was to identify interventions specifically designed to teach young people job related skills that may not have been identified during the first search as the keywords used initially were generic.

2.3.2 Inclusion/exclusion criteria

In order to be included in the review, interventions had to meet certain inclusion criteria. The review included interventions that:

- Were designed specifically for individuals with ASDs.
- Included at least one participant in the age range 14-21 years.
- Included exclusively participants without intellectual disability.
- Included exclusively participants who were able to speak and had age-appropriate vocabulary.

The review excluded interventions that:

- Were not designed specifically for individuals with ASDs.
- Did not include at least one participant in the age range 14-21 years.
- Included participants with intellectual disability.
- Included participants who were not able to speak or participants with limited vocabulary.
- Placed emphasis mainly on specific applications and delivery methods rather than the content of life skills to be acquired.
- Health-related interventions.
- Pharmacological interventions that used medication to modify behavior.

The review included peer-reviewed publications in English that were available up to November 2017. There were no other criteria regarding publication dates.

2.3.3 Selection of studies

Combined searches produced 2011 records, which were screened initially based on the information provided in the title and abstract. Ninety-five studies were initially selected, and 1919 studies met at least one of the exclusion criteria and were excluded. Thirty-two studies were subsequently eliminated as it became obvious from the main text that they met some of the exclusion criteria:

- Interventions that did not include participants in the age groups 14-21 years (11 studies e.g. Pennigton, Strange, Stenhoff, Delano, & Ferguson, 2012; Schimdt & Stichter, 2012).
- Interventions that included participants with intellectual disability and interventions that included participants who were not able to speak or had limited vocabulary (14 studies e.g. Valenti, Cerbo, Masedu, De Caris, & Sorge, 2010; Wu, Mirenda, Wang, & Chen, 2010).
- Interventions which placed emphasis on specific applications and delivery methods. These were describing training programs delivered through technological applications and specialized delivery methods (e.g. programs

using tablets or other electronic applications; program aiming to enhance skills through teaching participants how to make music compositions, 5 studies e.g. Greher, Hillier, Dougherty, & Poto, 2010; O'Handley, Roderick, Radley, & Whipple, 2015).

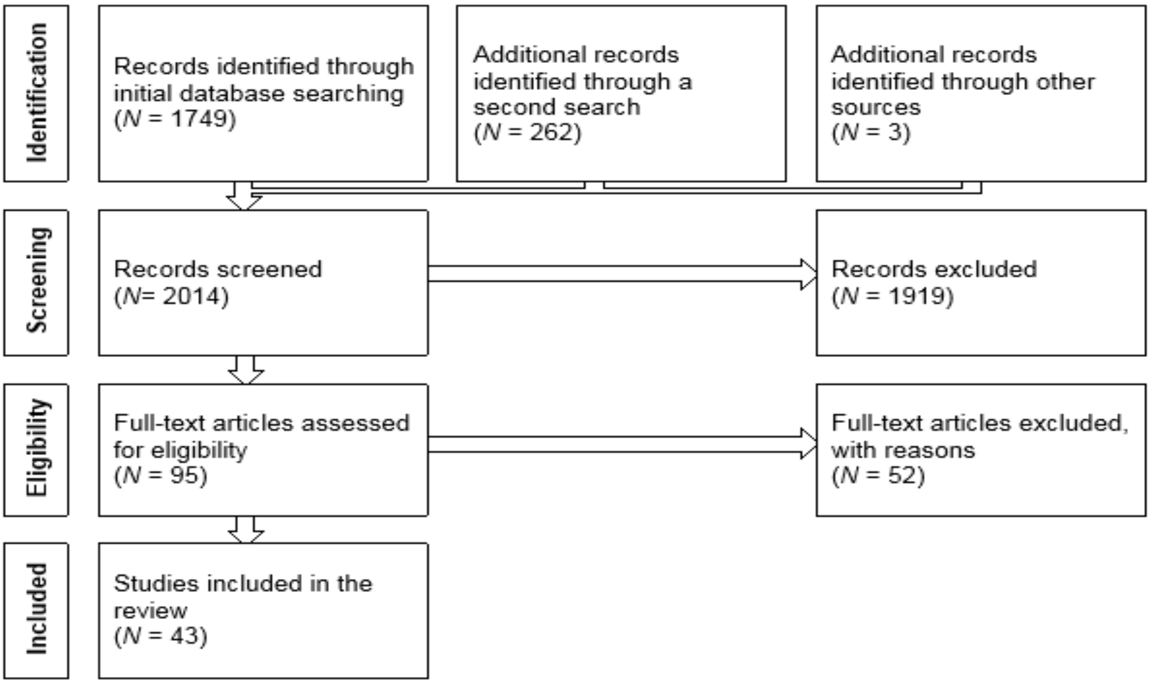
- Interventions that were not designed specifically for individuals with ASDs (2 studies e.g. Gardner, Mulry, & Chalik, 2012).

A further 20 studies were excluded because their content was not relevant to the aims of the review:

- Interventions focusing on specific job training (3 studies e.g. Palmen, Didden, & Korzillius, 2010; Wehman et al., 2013).
- Interventions providing instructions on teaching academic subjects (1 study, Whitby et al., 2013).
- Interventions providing parent training (9 studies e.g. Pillay, Anderson-Day, Wright, Williams, & Urwin, 2011; Schultz, Stichter, Herzog, McGhee, & Lierheimer, 2012).
- Interventions providing teacher training (1 study, McDonald & Hemmes, 2003).
- Interventions that were providing an overview of training programs without using outcome measures (5 studies e.g. Longhurst, Richards, Copenhaver, & Morrow, 2010; White, Koening, & Scahill, 2010); sensory programs (1 study, Gutman, Rafael-Greenfield, & Rao, 2012).

Three additional studies were identified through searching the reference sections of the included papers. A final total of 43 studies are included in the review. Figure 1 illustrates the study selection process.

Figure 1 : PRISMA Flowchart



2.3.4 Appraisal tool

The *Evaluative Method for Determining Evidence Based Practices (EBPs) in Autism (Reichow et al., 2008)* was applied to determine research report rigor and identify EBPs. This method was originally developed to identify practices that could be considered EBPs for young children with ASDs, and has also been applied to evaluate practices for older age groups (Reichow & Volkmar, 2010). The method includes three instruments:

1) Rubrics for the evaluation of research report rigor (Reichow, 2011). Two rubrics were developed, one for research conducted using group research design (GRD) and one for research conducted using single subject experimental design (SSED). The rubrics included two levels of methodological element.

   a. Primary quality indicators, which are the elements of research methodology deemed necessary for establishing the validity of a study, they are operationally defined and graded on a trichotomous scale (High Quality/Acceptable Quality/Unacceptable Quality).

   b. Secondary quality indicators, which although important, are not deemed necessary for establishing the validity of a study, they are operationally defined on a dichotomous scale, the report either contains or does not contain evidence of each indicator.

2) Guidelines for the evaluation of research report strength (Reichow, 2011). There are three levels of research report strength: 1) Strong: demonstrating concrete evidence of high quality; 2) Adequate: showing strong evidence in most but not all areas; 3) Weak: indicating that the report has missing elements or fatal flaws.

3) Criteria for determining if an intervention can be classified as an EBP (Reichow, 2011). Strength ratings across studies are combined to determine if a practice has gathered enough empirical support to be classified as an EBP. The EBP status formula $[(\text{Group}_{\text{S(number of group studies with strong rigor ratings)}} *30)+ (\text{Group}_{\text{A (number of group studies with adequate rigor ratings)}}*15)+(\text{SSED}_{\text{S(number of participants from SSED studies with strong rigor ratings}}*4)+ (\text{SSED}_{\text{A(number of participants from SSED studies with adequate rigor ratings)}} *2)=Z]$ is used to determine whether a practice is an established EBP (Z=60+); Probable EBP (Z=31-60); or not an EBP (Z=0-30). An established EBP is a treatment effective across multiple methodologically sound studies, conducted by at least two independent research groups in separate geographical locations. A probable EBP is shown to be effective across multiple studies but with weaker methodological rigor, fewer replications or inadequate number of independent researchers demonstrating the effects.

2.4 Results

Included studies were divided into four categories based on the specific life skills their proposed interventions aimed to teach. The categories were:

1. Peer relationships.
2. Social skills.
3. Self-management skills.
4. Life planning skills.

For each study, data were extracted on research aims, sample size, participants' ages, delivery agent, setting, density, research design, evidence of long-term implementation, evidence of follow up, outcome measures and results, country where the research was conducted and intervention type.

All interventions were rated for research report rigor and strength using the criteria of the *Evaluative Method for Determining EBPs*. Ratings in all the primary and secondary quality indicators of each intervention are included in Table 1 and Table 2 in Appendix A_2. Techniques and methods used by the practitioner during the sessions are described for all interventions. When various interventions applied similar methods and techniques they were collapsed into categories of intervention type and the EBP status formula was applied to determine if they can be classified as an EBP.

2.4.1 Peer relationships

Fourteen interventions were designed with the aim to promote efficacy in peer relationships (Table 3). They included participants in the age range 11-24 years and the majority received adequate ratings of research strength. Interventions reported significant improvement in the areas of social skills; social skills knowledge; social interaction; social functioning; anxiety; autistic symptoms; peer engagement; quality of life; psychosexual knowledge; parent-adolescent communication; participation in social activities. Two categories of intervention type were identified among these interventions: The Program for the Education and Enrichment of Relational Skills (PEERS) and the Tackling Teenage Training program (TTT).

PEERS (Gantman, Kap, Orenski, & Laugeson, 2012; Hill et al., 2016; Laugeson, Frankel, Mogil, & Dillon, 2009; Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012; Laugeson, Ellingsen, Sanderson, Tucci, & Bates, 2014; Laugeson, Gantman, Kapp, Orenski, & Ellingsen, 2015; Lordo et al., 2017; Schohl et al*.,* 2014; Yoo et al., 2014) is a manualized parent-assisted intervention, offering group training with the aim of instructing adolescents on key elements about making and keeping friends, managing conflict and peer rejection.

During didactic lessons participants received instructions and rehearsed targeted skills. Concurrent parent group sessions involved lessons on assisting adolescents to practice their newly learned skills in natural settings. PEERS has been delivered within a school setting as part of the regular classroom activities (Laugeson et al., 2014) and has been adopted for young adults (Gantman et al., 2012; Laugeson et al., 2015) with the inclusion of additional modules on romantic relationships and dating etiquette. The PEERS program is found to be an established EBP [(0x30)+(6x15)+(0x4)+(0x2)=90].

The PEERS program has a methodologically robust research design, involving nine replications of the intervention. Out of those replications, six were employing a quasi-experimental design and three were RCTs. It is an intervention that is highly manualized, thus making it easier to design comparable replications and investigate its effectiveness in different settings and with different age groups. PEERS has been applied by various independent research groups (e.g. Hill et al., 2016; Laugeson et al., 2009; Lordo et al., 2017; Schohl et al., 2014), in different geographical areas (California, New Orleans, Missouri, Wisconsin) and countries (USA, Korea), while the majority of studies included an adequate number of participants (*N*>10).

PEERs is a parent assisted intervention. However, the sessions with the parents along with the homework assignments they performed with their children were not described in detail. More information could have actually increased our understanding around the role that parents play in interventions designed to help their children along with the challenges and benefits that this involvement poses. PEERS has also been applied within a school with positive results (Laugeson et al., 2014). Once more, not enough details are provided regarding the process of transferring an intervention from clinical settings within schools. Only two interventions in this section were applied within schools (Koegel et al., 2012; Laugeson et al., 2014) Therefore, a more elaborate description of the factors that enable the implementation of an intervention within schools along with the views of the teachers who applied the intervention could have provided useful insights and inform the design of future studies.

Romantic and sexual relationships were addressed in three interventions. The TTT program (Dekker et al., 2015; Visser et al., 2017) is a category of intervention type offering individual training. Parents also received an overview of each session so that they could discuss or practice the appropriate set of skills with the young person. Sessions were highly structured including theoretical knowledge and practical applications. The TTT program is not currently found to be an EBP [(1x30)+(0x15)+(0x4)+ (0x2)=30].

TTT has a methodologically robust research design. It involved two replications of the intervention with one of them employing an RCT, while all replications were performed with an adequate number of participants (*N*>10). Like PEERS, TTT is a parent assisted intervention. However, the sessions with the parents along with the homework assignments they performed with their children were not described in detail.

There are well documented difficulties that parents face when they are trying to discuss sexuality with their children who have an ASD diagnosis (Ballan, 2012). Therefore, more information would have assisted researchers and practitioners to better understand how they can support parents to approach these issues with their children.

Corona, Fox, Christodulu, & Worlock (2016) also focused on sexual relationships. They offered group training sessions covering the topics of puberty; dating behaviour; personal hygiene; personal safety. Parents attended concurrent but separate sessions with the aim of providing them with strategies to support the adolescents.

In two interventions by Koegel et al. (2012) and Koegel, Ashbaugh, Koegel, Detar, & Regester (2013) the aim was to increase social interactions between young people with ASDs and their neurotypical peers in their school and college. Individuals were supported to access and participate in socialization opportunities such as lunch clubs based on their interests at their school (Koegel et al., 2012) or social events and activities of their choice in college, which they attended with a designated peer mentor (Koegel et al., 2013).

Table 3

Results of interventions for promoting peer relationship efficacy in young people with ASDs

Authors	Aims	Sample Size	Ages	Delivery Agent	Setting	Density	Research Design	Long term implementation	Follow up	Outcome measures and results			Country	Research Report Rigor	Intervention Type
										SI	NS	SV			
Corona et al. (2016)	Increase psychosocial knowledge; improve parent adolescent communication	8 (6 males/2 females)	12-16	Doctoral students/ Behaviour expert/ Masters in Education	Autism Centre	6x2 hour sessions in three months	GRD Pre-test Post-test	No evidence	No evidence	SBS, Parent Questionnaire	Adolescent Knowledge	Satisfaction Questionnaire positive	USA, New York	Weak	Sexuality educational program
Dekker et al. (2015)	Increase psychosexual knowledge	30 (23 male/7 female)	11-19	Trained and certified trainers of TTT	Clinic	60 min x 1 day weekly, 18 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	Psychosocial Knowledge Test		No evidence	The Netherlands	Weak	TTT
Gantman et al. (2012)	Improve social functioning, skills, knowledge; increase empathy, get togethers; reduce loneliness	17 (12 female/5 male	18-23	Clinical Psychologist/ Psychology Fellow	Mental Health Agency	90 min x 1 day weekly, 14 weeks in total	GRD RCT	No evidence	No evidence	SRS, SSRS SELSA, EQ, QSQ, TYASSK	SSI	No evidence	USA, California	Adequate	PEERS
Hill et al. (2016)	Improve social skills; reduce anxiety	5 (4 male/1 female)	13-15	Clinical Psychologist/ Post- doctoral Fellow	Community Agency	90 min x 1 day weekly, 14 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	SSIS, SRS-2, TASSK	SCARED	No evidence	USA, New Orleans	Weak	PEERS

Note. GRD: Group Research Design; SSED: Single Subject Experimental Design; SI: Significant Improvement (indicates statistical significance and when statistical measures were not used indicates areas with larger improvement); NS: Not Significant Improvement

Table 3 (continue)

Results of interventions for promoting peer relationship efficacy in young people with ASDs

Authors	**Aims**	**Sample Size**	**Ages**	**Delivery Agent**	**Setting**	**Density**	**Research Design**	**Long term implementation**	**Follow up**	**Outcome measures and results**			**Country**	**Research Report Rigor**	**Intervention Type**
										SI	**NS**	**SV**			
Koegel et al. (2012)	Increase social interaction	3 (male)	11-14	Undergraduate Psychology Students	School	No information	SSED Multiple Baseline across Participants	Intervention was applied in a different school when the pupil transitioned	No evidence	Percentage of partial interval of engagement, Frequency of initiations		No evidence	USA, California	Adequate	Structured socialization opportunities in the form of lunch clubs
Koegel et al. (2013)	Improve quality of life; increase participation in social activities	3 (male)	21-23	Clinician	Clinic/ University Campus/ Community	60 min x 1 day weekly, 33 weeks in total	SSED Multiple Baseline across Participants	Utilized existing resources	No evidence	Social Activities, Quality of Life		Satisfaction of socialization-positive	USA, California	Adequate	Structured social planning
Laugeson et al. (2009)	Improve social functioning; increase social skills knowledge, get togethers	17 (15 male/2 female)	13-17	Clinical Psychologist	No information	90 min x1 day weekly, 12 weeks in total	GRD Treatment Group Delayed Treatment Group	No evidence	No evidence	SSRS, TASSK, FQS, QPQ		No evidence	USA, California	Weak	PEERS
Laugeson et al. (2012)	Improve social functioning; increase social skills knowledge, get togethers	14 (12 male/5 female)	12-17	Clinical Psychologist	No information	90 min x 1 day weekly, 14 weeks in total	GRD Treatment Group Delayed Treatment	No evidence	14 weeks	SSRS, SRS, QPQ, TASSK-R		No evidence	USA, California	Weak	PEERS
Laugeson et al. (2014)	Improve social skills, social responsiveness, peer engagement	40 (37 male/3 female)	12-14	Teachers	School	30 min x 5 days weekly, 14 weeks in total	GRD Treatment Group Active Treatment Group	No evidence	No evidence	SRS, QPQ, SAS, TASSK	SSRS, FQS, PHS-2	No evidence	USA, California	Adequate	PEERS

Table 3 (continue)

Results of interventions for promoting peer relationship efficacy in young people with ASDs

Authors	Aims	Sample Size	Ages	Delivery Agent	Setting	Density	Research Design	Long term implementation	Follow up	Outcome measures and results			Country	Research Report Rigor	Intervention Type
										SI	**NS**	**SV**			
Laugeson et al. (2015)	Improve social skills, social responsiveness, peer engagement	12 (10 male/2 female)	18-24	Clinical Psychologist/ Post-doctoral Clinical Fellow	Community Mental Health Setting	90 min x 1 day weekly, 16 weeks in total	GRD RCT	No evidence	No evidence	TYASSK, SRS, SSRS, QSQ	EQ	No evidence	USA, California	Adequate	PEERS
Lordo et al. (2017)	Improve socio-emotional functioning	16 (12 male/4 female)	12-17	No information	University Hospital	90 min x 1 day weekly, 14 weeks in total	GRD ASD Group Typical Developing Group	No evidence	No evidence	BASC-2, GARS	NEPSY-II, ERICA, PANAS-C, PANAS-C-P	No evidence	USA, Missouri	Adequate	PEERS
Schohl et al. (2014)	Increase get togethers; improve quality of friendships; decrease levels of anxiety and autistic symptoms	29 (24 male/5 female)	11-16	Author/ Clinical Psychology Graduate Students/ Research Assistants	No information	90 min x 1 day weekly, 14 weeks in total	GRD Treatment Group Waitlist Group	No evidence	No evidence	TASSK, QSQ, SRS, SSRS, SIAS	FQS	No evidence	USA, Wisconsin	Adequate	PEERS
Visser et al. (2017)	Increase psychosexual knowledge; improve behavior	95 (73 male/22 female	12-18	Professionals in Psychology/ Social Sciences	No information	60 min x1 day weekly, 18 weeks in total	GRD RCT	No evidence	12 months	Psychosexual Knowledge Test, SRS, CBCL, Parent reported scale	Self-report scale	No evidence	The Netherlands	Strong	TTT
Yoo et al. (2014)	Improve social functioning, skills and knowledge; decrease depressive symptoms	28 (26 male/2 female)	12-18	Psychiatrists/ Clinical Psychologist SEN Teachers	No information	90 min x 1 day weekly, 14 weeks in total	GRD RCT	No evidence	3 months	ADOS, TASSK-R, QPQ, CDI, K-CBCL, STAIC-S, STAIC-T, SCQ, SSRS, EHWA-VABS		No evidence	Korea	Adequate	PEERS

2.4.2 Social skills

Sixteen interventions were designed with the aim to improve efficacy in social skills (Table 4). They included participants in the age range 6-28 years and the majority received weak ratings of research strength. Their results indicated significant improvement in the areas of question asking; affect recognition; awareness of other people’s thoughts and feelings; social communication; facial expression recognition; cognitive functioning; anxiety; depression. Three groups of intervention type were identified among these interventions: The Aspirations Program, Applied Behavioral Analysis (ABA) and Social Skills Group Training.

The majority of interventions applied a group training format (Herbrecht et al., 2009; Hillier, Fish, Cloppert, & Beversdorf, 2007; Hillier, Fish, Siegel, & Beversdorf, 2011; Lerner, Mikami, & Levine, 2011; McMahon, Vismara, & Solomon, 2013; Minihan, Kinsella, & Honan, 2011; Mitchell et al., 2010; Palmen, Didden, & Arts, 2008; Stichter et al., 2010; Tse, Strulovich,Tagalakis, Meng & Fombonne, 2007; Vernon, Miller, Ko, & Wu, 2016; Webb, Miller, Pierce, Strawser, & Jones*,* 2004; White et al., 2010). In Argott, Townsend, Sturmey, and Poulson (2008) and Day –Watkins, Murray, and Connell (2014) the training was delivered through individual sessions between the trainer and the young person.

Mitchel et al. (2010) included a parent component where parents attended concurrent but separate sessions and assisted young people with practicing newly learned skills. McMahon et al. (2013), Minihan et al. (2011) and White et al. (2010) enlisted the assistance of typically developing peers who modeled the targeted skills for the group. Minihan et al. (2011) designed a Bahavioural Consultation Model with the aim to train teachers and teaching assistants, who also delivered the intervention in a learning support classroom.

The Aspirations Program (Hillier et al., 2007; 2011) is a category of intervention type offering a combination of vocational and social skills training with the aim of improving social skills and reducing anxiety. Sessions were organized around predetermined topics and were directed by group members, although program facilitators were also present to provide assistance. The Aspirations Program is not currently found to be an EBP [(0x30) + (0x15)+(0x4)+ (0x2)=0].

A second group of intervention type is Social Skills Group Training (Herbrecht et al., 2009; McMahon et al., 2013; Minihan et al., 2011; Stichter et al., 2010; Tse et al., 2007; Vernon et al., 2016; Webb et al., 2004; White et al., 2010). Training programs included at least two peers of similar age and followed a structure which consisted, with some variations, of the following elements: 1) review of homework and previously learned skills; 2) topic discussion and demonstration of a new social skill; 3) opportunities for skills practice within the group; 4) a period of unstructured socialization time; 5) assignments where young people were advised to practice the learned skills in the community.

The majority of the programs had a fixed structure (McMahon et al., 2013; Minihan et al., 2011; Stichter et al., 2010; Tse et al., 2007; Vernon et al., 2016; Webb et al., 2004; White et al., 2010) while Herbrecht et al. (2009) introduced a more flexible format depending on the needs of the group. Social Skills Group Training is not currently found to be an EBP [(0x30)+(0x15)+(0X4)+(0X2)=0].

A third group of intervention type is ABA (Argot et al., 2008; Day-Watkins et al., 2014; Palmen et al., 2008). Programs employed: 1) discrete trial teaching; 2) prompting and fading techniques; 3) reinforcement and generalization strategies. Their aims were to increase the use of empathic statements (Argot et al., 2008), helping responses (Day-Watkins et al., 2014) and question asking (Palmen et al., 2008). ABA is not currently found to be an EBP [(0x30)+(0x15)+(0X4)+(15X2)=30].

Table 4

Results of interventions for promoting social skills efficacy in young people with ASDs

Authors	**Aims**	**Sample Size**	**Ages**	**Delivery agent**	**Setting**	**Density**	**Research Design**	**Long term implementation**	**Follow up**	**Outcome measures and results**			**Country**	**Research Report Rigor**	**Intervention Type**
										SI	**NS**	**SV**			
Argott et al. (2008)	Increase Empathic statements	3 (2 male/ 1 female)	11-14	Instructor	School	15 min (24 trials) x three days weekly	SSED Multiple Baseline across Participants	No evidence	6 weeks	Empathic statements		No evidence	USA, New York	Adequate	ABA
Day Watkins et al. (2014)	Increase Helping responses	3 (male)	13-18	Experimenter	School office	18 trials in each session	SSED Multiple Probe Design across Participants	No evidence	8 weeks	Helping responses		No evidence	USA, New Jersey	Adequate	ABA
Herbrecht et al. (2009)	Improve communication and social interaction skills; reduce autistic symptoms	17 (15 male/ 2 female)	8-19	Child Psychiatrists/ Clinical Psychologists	Clinic	Children group 60 min x 1day weekly, 29 sessions in total Two Adolescent groups: 90 min x 1 day every two weeks Experienced: 17 sessions /Naïve 15 sessions in total	GRD Pre-test Post-test	No evidence	12 weeks	DCL, GAS, SKS, PIA-CVmini	CGB, FaBel, FEG, Video rating	No evidence	Germany	Weak	Social skills group training
Hillier et al. (2007)	Increase understanding of social, vocational issues, insight and awareness; provide social opportunities	13 (11 male/ 2 female)	18-23	Multidisciplinary team	No information	60 min x 1 day weekly, 8 weeks in total	GRD Pre-test Post-test	Monthly sessions after the end of the program	No evidence	EQ, Observations, Qualitative information	IPR, AQ	No evidence	USA, Massachusetts	Weak	Aspirations

Note. GRD: Group Research Design; SSED: Single Subject Experimental Design; SI: Significant Improvement (indicates statistical significance and when statistical measures were not used indicates areas with larger improvement); NS: Not Significant Improvement

Table 4 (continue)

Results of interventions for promoting social skills efficacy in young people with ASDs

Authors	Aims	Sample Size	Ages	Delivery Agent	Setting	Density	Research Design	Long term implementation	Follow up	Outcome measures and results			Country	Research Report Rigor	Intervention Type
										SI	NS	SV			
Hillier et al. (2011)	Reduce anxiety and depression	49 (42 males/7 females)	18-28	Authors/ Graduate or Undergraduate student	University	60 min x 1 day weekly, 8 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	BDI, STAI		No evidence	USA, Massachusetts	Weak	ASPIRATIONS
Lerner et al. (2011)	Improve social functioning and receptive non-verbal cue reading; reduce depression	17(14 male/3 females)	11-17	Service Staff in Spotlight Summer Program	Community	5 hours daily x 6 weeks, 29 sessions in total	GRD Treatment Group, Control Group	No evidence	Follow up – time not specified	SSRS, EDI, DANVA-2	SRS, CBCL, BDI-Y	Satisfaction survey-positive	USA, Virginia	Adequate	Sociodramatic effective relational therapy
MacKay et al. (2007)	Improve social communication	46 (38 male/8 females)	6-16	Multidisciplinary team	School	90 min weekly, 12 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	VABS,SSQ-P, SCPQ-P, SSQ-PU, SCPQ-PU, Parent ratings		Follow up interview-positive	UK	Weak	Groupwork including games, group discussion and role play
McMahon et al. (2013)	Increase initiating and response vocalizations	14 (9 males/5 females)	10-16	No information	Clinic	90 min x 1 day weekly, 22 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	Social behaviour summary scores		No evidence	USA, California	Weak	Social skills group training
Minihan et al. (2011)	Improve social skills	5(4 male/1 female)	15-16	Teachers	School	40 min sessions, 10 sessions in total	GRD Controlled Case Study Design with Replication	Trained teachers and teaching assistants	No evidence	SRS		Satisfaction Survey,-positive, IRP15, positive CEF-positive	Ireland	Weak	Social skills group training

Table 4 (continue)

Results of interventions for promoting social skills efficacy in young people with ASDs

Authors	Aims	Sample Size	Ages	Delivery Agent	Setting	Density	Research Design	Long term implementation	Follow up	Outcome measures and results			Country	Research Report Rigor	Intervention Type
										SI	NS	SV			
Mitchel et al. (2010)	Increase and maintain targeted social skills	3 (2 female/1 male)	15-19	Behaviour Consultants	Community Support Service	2 hours x 1 day weekly, 12 weeks in total	SSED Single Case Multiple Baseline	No evidence	3 months	SSRS	QOL, Observations	Satisfaction Survey-positive	USA, Ontario	Weak	Behavioural group social skills training program
Palmen et al. (2008)	Improve question asking	9 (7 male/2 female)	17-25	Trainer	Therapy room	60 min x 1 day weekly, 6 weeks in total	SSED Multiple Baseline across Skills	No evidence	1 month	Percentage of correct questions during a tutorial conversation	Response efficiency	Feedback Survey-positive	The Netherlands	Adequate	ABA
Stichter et al. (2010)	Improve social abilities, facial expression recognition, theory of mind and executive functioning	27 (males)	11-14	Master's level implementers	Treatment Centre for Autism	60 min x 5 sessions, 2 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	Faux Pas Stories, SRS, Reading the Mind in Eyes Test, TOPS-3-, BRIEF, DANVA-2-CF	Sally Ann Test, Smarties, Test, The Friends ABC Story	No evidence	USA, Missouri	Weak	Social skills group training
Tse et al. (2007)	Increase social competence	44 (27 male/17 female)	13-18	Clinical Psychologist/ Social Worker	Clinic	90 min x1 day weekly, 14 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	SRS, ABC, N-CBRF		Feedback Survey-positive	Canada	Weak	Social skills group training

2.4.3. Self-management skills

Nine interventions were designed with the aim to improve efficacy in self-managements skills (Table 5). They included participants in the age range 10-65 years and the majority received adequate or strong ratings of research strength. Studies reported significant improvement in the areas of psychological distress; anxiety; quality of life; depression; hyperactivity; ruminations; positive affect. One group of intervention type was identified among these interventions: The Multimodal Anxiety and Social Skills Intervention (MASSI).

The majority of interventions applied a group training format utilizing the approaches of Cognitive Behavioral Therapy, Meditation and Mindfulness (Cashin, Browne, Bradbury, & Mulder, 2013; Clarke, Hill, & Charman, 2016; Goodman, Corkum & Johnson, 2017; Pahnke, Lundgren,Hursti, & Hirvikoski, 2014; Santomauro, Sheffield, & Sofronoff, 2016; Spek, van Ham, & Nyklicek, 2013), while Cashin et al. (2013) used Narrative Therapy. In Garcia Villamisar and Dattilo (2010) participation in recreational activities was also used as a means to ease the symptoms of anxiety and depression. Goodman et al. (2017) provided group training for parents.

MASSI (White, Ollendick, Scahill, Oswald, & Albano, 2009; White et al., 2013) is a group of intervention type targeting anxiety and social deficits concurrently while combining group and individual training. The intervention enlisted the assistance of neurotypical peers who modelled the skills and provided feedback. It also included a parent component with parents acting as coaches in exercises assigned to the young people. MASSI is not currently found to be an EBP [(1x30)+(0x15)+(0X4)+(0X2)=30].

Table 5

Results of interventions for promoting self-management efficacy for young people with ASDs

Authors	Aims	Sample Size	Ages	Delivery Agent	Setting	Density	Research Design	Long term implementation	Follow up	Outcome measures and results			Country	Research Report Rigor	Intervention Type
										SI	NS	SV			
Cashin et al. (2013)	Reduce stress related problems	10 (9 male/1 female)	10-16	Mental Health Nurse	Health Centre	60 min x 1 day every two weeks, 5 sessions in total	GRD Pre-test Post-test	No evidence	No evidence	K-10	SDQ, BHS, The salivary cortisol DHEA	No evidence	Australia	Weak	Narrative Therapy
Clarke et al. (2016)	Reduce stress; improve copying mechanisms; reduce avoidance strategies	28 (male)	11-14	Author/ doctoral student	School	60 min x 1 day weekly, 6 weeks in total	GRD Randomized Control Trial	No evidence	No evidence	SCAS-P, SCAS-C CSCY		Interviews-positive	UK	Adequate	Cognitive Behavioural Therapy
Garcia Villamisar & Dattilo (2010)	Improve quality of life; reduce stress	37(22 male/15 female)	17-39	No information	Learning Centre/ Community Centre	2 hours x 5 days weekly, 12 months in total	GRD Treatment Group Control Group	No evidence	No evidence	QOL, SSS		No evidence	Spain	Weak	Group leisure program
Goodman et al. (2017)	Increase knowledge about personal strengths and challenges	8 (no information on gender)	14-17	No information	No information	90 min x 7 sessions	SSED Pre-test Post-test	No evidence	No evidence		PHCSCS-2, CDI-2	Satisfaction interview-positive	Canada	Weak	Metacognitive training

Note. GRD: Group Research Design; SSED: Single Subject Experimental Design; SI: Significant Improvement (indicates statistical significance and when statistical measures were not used indicates areas with larger improvement); NS: Not Significant Improvement

Table 5 (continue)

Results of interventions for promoting self-management efficacy for young people with ASDs

Authors	Aims	Sample Size	Ages	Delivery Agent	Setting	Density	Research Design	Long term implementation	Follow up	Outcome measures and results			Country	Research Report Rigor	Intervention Type
										SI	NS	SV			
Pahnke et al. (2014)	Reduce stress and emotional distress; increase psychological flexibility	15 (6 male/6 female)	13-21	Graduate Psychology student /Teacher	Special Education Needs School	2 x 40 min sessions weekly and 6-12 minutes of daily, mindfulness exercises 6 weeks in total	GRD Intervention Group Control Group	No evidence	2 months	SSS BYI	SDQ	Evaluation Survey-positive	Sweden	Adequate	Acceptance and Commitment Therapy
Santomauro et al. (2016)	Reduce depression	20 (12 males/8 females	Mean Age: 16	Clinical Psychologist	No information	60 min x 11 sessions	GRD RCT	No evidence	No evidence	DASS ERQ	BDI	Feedback interviews-positive	Australia	Adequate	Cognitive Behavioural Intervention
Spek et al. (2013)	Decrease depression, anxiety and rumination; increase positive affect	20 (13 male/7 female)	18-65	Psychologist/ Clinical Psychologist	Health Centre	2 ½ hours weekly, 9 weeks in total	GRD RCT	No evidence	No evidence	SCL-90-R, RRQ, GMS		No evidence	The Netherlands	Adequate	Mindfulness based therapy
White et al. (2009)	Reduce anxiety; improve social functioning	4 (2 males/2 females)	12-14	No information	No information	13 individual sessions over 11 weeks, 5 group sessions	SSED Clinical Replication of Four Cases	No evidence	No evidence	CASI-20, ADIS -C	SRS, MASC	No evidence	USA, Virginia	Weak	MASSI
White et al. (2013)	Reduce anxiety; improve social functioning	15 (11 male/4female)	12-17	Author/ Doctoral Students	Clinic	13 individual sessions over 11 weeks, 7 group sessions	GRD Treatment Group Control Group	No evidence	No evidence	SRS, DD-CGAS	CASI-Anx, PARS, CGI-I	Satisfaction Survey-positive	USA, Virginia	Strong	MASSI

2.4.4 Life planning skills

Four studies were designed with the aim to improve efficacy in life planning skills and to assist young people navigate through the demands of adulthood (Table 6). The majority received a weak rating of research strength. They focused on broad areas such as goal setting; life mapping; independent living; community involvement; education and work. Studies included participants in the age range 13-36 years and reported significant improvement in the areas of self-determination; future expectations; decision making ability; social and pragmatic skills. Curtin et al. (2015) and Siew, Mazzucchelli, Rooney, and Girdrel (2017) used peer mentoring while Fullerton and Coyne (1999) employed a group training format and Morgan, Leatzow, Clark, and Siller (2014) offered individual sessions. No categories of intervention type were identified among these interventions as they were applying very diverse techniques and methods.

Table 6

Results of interventions for promoting life planning efficacy in young people with ASDs

Authors	Aims	Sample Size	Ages	Delivery Agent	Setting	Density	Research Design	Long term implementation	Follow up	Outcome measures and results			Country	Research Report Rigor	Intervention Type
										SI	NS	SV			
Curtin et al. (2015)	Develop problem-solving, self-motivational, interpersonal, and social skills	9 (7 male/2 female)	13-18	Mentors	Community Centre	2 hours weekly, 20 weeks in total	GRD Pre-test Post-test	No evidence	No evidence		PedsQL RSES, SWQ	1)Youth Survey: Measuring the Quality of Mentor-Youth Relationship-satisfaction 2)Satisfaction Survey-positive	USA, Massachusetts	Weak	Partner Exploring Education and Recreation Mentoring program
Fullerton and Coyne (1999)	Develop knowledge and skills for self-determination	23 (10 female/13 male)	16-28	No information on delivery agent	No information on setting	2-3 hours weekly, 10 weeks in total	GRD Pre-test Post-test	No evidence	No evidence	Interviews: impact on communication/ self-knowledge/ life planning		Student evaluation-positive	USA, Massachusetts	Weak	Putting feet on my dreams self-determination program
Morgan et al. (2014)	Increase social and pragmatic skills; reduce depressive symptoms	13 (12 males/1 female)	18-36	Author	No information on setting	90 min x 1 day weekly, 12 weeks in total	GRD Treatment Group Control Group	No evidence	No evidence	Mock job interviews	VABS, PHQ-9	No evidence	USA, Florida	Adequate	Interview skills curriculum
Siew et al. (2017)	Improve well being, academic success, retention in university studies	10 (7 male/3 female)	17-20	Peer mentors	University	No information on density	GRD Pre-test Post-test	No evidence	No evidence	SPS PRCA-24	CSMP, AMAS-C, SCAM	Student Satisfaction Survey, Interviews-positive	Australia	Weak	Curtin Specialist Mentoring Program

Note. GRD: Group Research Design; SSED: Single Subject Experimental Design; SI: Significant Improvement (indicates statistical significance and when statistical measures were not used indicates areas with larger improvement); NS: Not Significant Improvement

2.5 Discussion

The review included a diverse set of interventions all of which aimed to improve functioning in young people with ASDs. Their outcomes are promising with improvements being reported in the various areas they tried to address. However, the majority were awarded a weak rating of research strength with only two interventions (Visser et al., 2017; White et al., 2013) receiving a strong rating.

Five intervention type categories were identified but only one, the PEERS program, met the criteria as an established EBP. Three interventions, MASSI, TTT and ABA are very promising although, currently they do not meet the criteria to be classified as established EBPs. More replications from different research teams are required for these interventions to amass adequate empirical support.

Social skills group training was not found to be an EBP. This finding is somewhat surprising since social skills group training is well established with other populations and is widely accepted as a component of various approaches to the treatment of emotional, behavioural and developmental disorders (Spence, 2003). The review focused on interventions for high functioning young people with ASDs and therefore, an evaluation was based on a very specific population and age range. However, when taking under consideration the impact of social skills group training on other populations it could be argued that the low ratings in this instance should be interpreted with caution.

Despite their low ratings, interventions showed positive outcomes something that could reflect the need for more methodologically robust studies in the future. Regardless of their individual ratings and EBP status, interventions also shared certain methodological shortcomings related to their applicability in school settings, limited evidence of long-term implementation and limited use of social validation procedures.

School Implementation

A limited number of interventions took place in schools (Argot et al., 2008; Clarke et al., 2016; Day-Watkins et al., 2014; Koegel et al., 2012; Laugeson et al., 2014; MacKay et al., 2007; Minihan et al., 2011; Pahnke et al., 2014) and only three of those were delivered as part of the regular activities. Laugeson et al. (2014) applied the PEERS curriculum in a regular classroom, Minihan et al. (2011) delivered the training during a learning support classroom and Koegel et al. (2012) utilized the existing lunchtime clubs in the school.

In the case of high functioning young people, where limited services are available to them after they leave school, secondary educational settings could be one of the few places where we can teach them the much-needed life skills that would allow them to lead independent adult lives. Furthermore, an increasing number of young adults with ASDs attend university and other further or higher education institutions. Student services departments exist to provide assistance with various non-academic issues, in a general sense, to all students. Other departments such as disability services can provide additional support with academic tasks, such as taking exams and attending lectures.

Currently there is not really training or support available to help young adults acquire the life skills that will enable them to move into employment or independent living. However, with adequate adjustments to the current system, universities and further education colleges could provide excellent opportunities for teaching these skills. Students with ASDs have expressed the need for a number of additional supports from universities, including informal social support especially in the beginning of their studies, better understanding among their peers regarding ASDs, and small special interest groups that would help them socialize (Casement, Carpio de los Pinos, & Forrester-Jones, 2016).

Long term Implementation

Few interventions provided evidence/indications of long-term implementation. Hillier et al. (2007) offered monthly sessions for young people and monthly support groups for parents after the end of the program. However, they provided no information regarding how many further sessions were offered, whether participants were attending regularly and if there were any additional benefits.

Minihan et al. (2011) designed a Behavioral Consultation Model with the main aim to provide teachers and teaching assistants with the skills that they could use to support other students in the future. The program was considered acceptable by the staff, but no evidence was provided as to whether teachers who received the training were able to implement the program with a different group of students. Koegel et al. (2012) applied the same program in a different school and Koegel et al. (2013) used existing university resources with positive results.

Less than half of the studies provided information on maintenance of the learned skills and collected outcome measures after the end of the program (Argott et al., 2008; Day Watkins et al., 2014; Herbrecht et al., 2009; Koegel et al., 2012; Laugeson et al., 2014; Lerner et al., 2011; Mitchel et al., 2010; Pahnke et al., 2014; Palmen et al., 2008; Visser et al., 2017; White et al., 2010; Yoo et al., 2014). Maintenance of the learned skills is crucial in order to evaluate the outcomes of the training programs therefore more interventions should include similar procedures.

Social validation

A number of interventions used self-reports/interviews and questionnaires after the implementation of the training program. (Clarke et al., 2016; Corona et al., 2016; Curtin et al., 2015; Fullerton & Coyne, 1999; Goodman et al., 2017; Koegel et al., 2013; Lerner et al., 2011; MacKay et al, 2007; Minihan et al.,2011; Mitchel et al., 2010; Pahnke et al., 2014; Palmen et al., 2008; Santomauro et al., 2016; Siew et al., 2017; Tse et al., 2007; Vernon et al., 2016; Webb et al., 2004; White et al., 2010;2013).Their aim was to investigate the views of participants and their parents regarding their satisfaction with the program along with their comments and suggestions for improvements.

Views of participants who receive the training are crucial as they are the ones who need to apply the skills and strategies they have learned and can experience the potential benefits in their daily lives. However, there is an important issue when assessing the acceptability of a training program after it has been implemented. This can be described as the “Social Placebo Effect”, with parents potentially feeling overly satisfied when their children are receiving any type of treatment, possibly regardless of the actual outcomes. This may reflect carer gratitude toward receiving any program, which could be perceived to be potentially helpful.

Only one study used a validated measure to assess acceptability by the practitioners who delivered the intervention. Minihan et al. (2010) used IRP-15 to assess treatment acceptability as perceived by teachers who implemented the intervention. The views and experiences of those who receive and implement the interventions are important and these should be included as part of the social validation process.

A significant number of interventions took place in clinics and those who delivered them were working closely with the research team. However, scientific evidence that a program is effective is not enough to promote acceptability among practitioners. Perceptions that practitioners hold about evidence-based practices can be problematic as over the years they have being asked to apply a number of different and often conflicting practices (Camine, 2000). Reflecting this, a US based study documented that special education needs teachers reported that they would keep using instructional practices they believe are effective disregarding the endorsed instructional programs (Boardman, Arguelles, Vaughn, Hughes, & Klinger, 2005).

Not all interventions assessed consumer satisfaction and acceptability and none of them applied social validation procedures to inform their initial design and application. Researchers are making their decisions regarding study design based on what they believe are the skills that young people and their families need. These findings are in line with Callahan, Henson, and Cowan (2008) who argue that in the area of ASDs there is a striking absence of social validity research. Future programs should investigate and take into consideration the views and needs of young people, their parents and those of the practitioners as these are essential in designing programs that are considered useful and also appealing by the population they aim to reach.

2.6 Strengths and limitations

The literature review looked into life skills interventions designed specifically for high functioning young people with ASDs. Therefore, it contributed towards a better understanding of the training available for a population within the autism spectrum but with its own specific needs. The review also evaluated interventions targeting various life skills rather than distinguishing between specific types of training, thus offering insights into a wider field of research compared with previous literature reviews.

The review included interventions targeting participants without intellectual disability who were also able to speak and had age appropriate vocabulary. This combination of criteria limited the results to a very specific pool of studies. It is possible that interventions designed for young people with intellectual disability and/or those who are unable to speak or have limited vocabulary could also be beneficial for those on the high functioning end of the spectrum. The keywords that were used in the literature search have also resulted in a specific selection of studies and a different choice of keywords could have influenced the final outcome.

The review also focused on interventions developed specifically for young people with ASDs however, programs developed for other groups could also be effective for this population. Finally, the focus of the review was the content of life skills programs and as a result studies that placed emphasis on specific applications and delivery methods were excluded. However, these programs could also possibly be useful for young people with ASDs.

2.7 Conclusion

Individuals with ASDs, parents and practitioners have identified desired outcomes and areas of priority including social skills, self-care, emotional and behavioural maturity, friendships, relationships, educational opportunities and employment (Pellicano et al., 2014) among their desired outcomes. Interventions included in the current review focus broadly on these areas, which is an indication that despite the existing challenges scientific research is not entirely out of touch with the needs of young people with ASDs and their parents. However, the various methodological shortcomings of the interventions combined with the negative outcomes for adults with ASDs and an expressed need by parents and practitioners for evidence-based practices (Goin-Kochel, Myers, & Mackintosh,2007) are all cumulative indications that more efforts should be made to further inform and improve the design of future interventions.

2.8 Rationale for next chapter

Review of the current life skills interventions revealed certain shortcomings and limitations regarding social validation procedures, evidence of applicability in a school setting and evidence of long-term implementation. These findings were the basis for the next chapter which describes the research aims and methodology adopted for this thesis in order to try to address these issues.

Chapter 3: Methodology

3.1 Chapter summary

Literature review revealed certain shortcomings of life skills interventions, particularly regarding their social validation procedures; evidence of school implementation; and evidence in relation to their potential for long term implementation. In an attempt to address these issues, the thesis employed a mixed methods approach utilizing qualitative (interviews, focus groups) and quantitative (cross-sectional survey) research methods. In order to highlight the reasons behind the choice of the mixed methods approach the traditional research approaches are being debated and a justification is offered for the choice of the research method in each phase of data collection. Issues around validity and reliability, particularly in connection to qualitative paradigm, are also discussed.

3.2 Introduction

A review of the literature revealed certain shortcomings of life skills interventions that have been developed for high functioning young people with ASDs. These included: limited use of social validation procedures; limited evidence regarding their applicability within a school setting; limited evidence regarding their potential for long term implementation. The voices of those who receive the interventions, the young people with ASDs and their parents, are mostly absent from the literature. Therefore, it was considered crucial to acquire their views in relation to life skills training and support that is currently available to them, and also their training needs in order to achieve their desired outcomes later in life.

Limited evidence regarding the implementation of interventions in schools, compared to those that were implemented in clinical settings, highlighted the need to investigate life skills provision in schools. It was considered that this aim will be best met by consulting with those responsible for supporting the pupils and delivering the training. Therefore, the views of education providers regarding the life skills training they offer to their pupils, the challenges they face and their recommendations for improvements were explored.

Investigating current practices in schools along with the needs and experiences of young people and their parents could assist in developing interventions that are meaningful to their recipients and will also build on the existing resources and expertise. Acceptability by education providers, parents and young people could increase their willingness to implement and receive those interventions.

The overall aim of the thesis was to investigate life skills provision in the UK, with an emphasis on school provision, and contribute to the improvement of current practices by providing recommendations for research and practice. The choice of any methodological design presents a range of challenges and possibilities for researchers. Therefore, an informed decision needs to be made and this requires consideration and thought. I chose to employ a pragmatic approach (Morgan, 2013), linking the research questions and research methods at every step.

This has offered me the freedom to utilise methods and procedures typically associated with qualitative and quantitative paradigm in a mixed methods study model. I acknowledge that any methodological approach adopted for this thesis would have shaped the outcome of the research, therefore this chapter will present a rationale for the use of the mixed methods approach, discussing its strengths and limitations.

3.3 Debating traditional approaches to research

In order to decide on research methodology, one should start by considering the different research traditions and their basic principles. There is a fundamental debate in social sciences over how best to study and understand the world. In its most extreme form the root of the debate can be found in the different philosophical views about the nature of reality and it can be expressed as logical positivism versus phenomenology or quantitative versus qualitative methods. This is often called "the paradigms debate" with a paradigm being a particular worldview (Patton,1999).

A sharp distinction exists between qualitative and quantitative approaches in terms of their fundamental assumptions about the world and how it can be studied. According to Edmund Husserl (1887-1938), the founder of phenomenology, methods of natural sciences cannot be applied to study the human consciousness. From the phenomenological standpoint, objects in the external world cease to exist independently and people can only be certain about how things present themselves to their consciousness. Therefore, we can only achieve certainty and knowledge by ignoring everything outside our immediate experience, and in this way the external world is being reduced to the contents of personal consciousness (Fouche, 1993).

If we could summarize the aim of the phenomenological method in one question this question would be “What is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people” (Lyncoln & Cuba:104, 2002). Grounded in the tradition of phenomenology, the primary aim of qualitative research is to develop an understanding of how the world is constructed (McLeod, 2008).

The word “constructed” implies that there is a social and relational world that is complex, layered and can be viewed from different perspectives. For the qualitative researcher, the only reality is the one constructed by the individuals involved in the research situation and therefore, he or she is required to report faithfully those realities. In this theoretical context, every form of knowledge is temporary as we can never achieve a complete “scientific” understanding of the human world. We can only arrive at a truth that makes a difference and opens up new possibilities for knowledge (McLeod, 2008).

Qualitative research is fundamentally interpretative. This entails analyzing the data for themes or categories and making interpretations about their meanings personally and theoretically (Creswell, 2003). As qualitative analysis depends on pattern recognition, it can be considered a creative process where the insights and understanding of the analyst play a prominent role (Patton, 1999). As a result, personal interpretation is intertwined with qualitative analysis (Creswell, 2003). Indeed, phenomenologists believe that researchers cannot escape their own assumptions and that they should not pretend otherwise (Hammersley, 2000).

This is widely recognized in qualitative enquiry and what is required from the researcher is to acknowledge his or her bias, interests and values in a process that is known as reflexivity (Creswell, 2003). It has been suggested that a reflective journal should be kept to monitor feelings, ideas, and reactions throughout the research process (Ortlipp, 2008).

Because the researcher is the instrument of qualitative enquiry at this point, I believe that it would be useful for the reader to acquire some information about my background. I grew up in Greece where I completed a BSc in Psychology. Then I moved to the UK where I continued my studies obtaining an MSc in Counselling Psychology and an MRes. As part of my studies I undertook research projects where I conducted focus groups with adolescents and adults, exploring various aspects of the social and personal sphere. Furthermore, I have worked as a counsellor with children, adolescents and adults. However, I had no experience in learning disabilities, including ASDs.

My own experiences and training could have had both positive and negative influences on the research process. Therefore, it was important to acknowledge their potential impact before embarking on my project. Having no prior experience in ASDs either as a researcher or a counsellor, meant that I was largely free of personal views and perceptions which may have coloured my data.

My counselling experience would have enabled me to engage with participants, particularly with the young people, and elicit their narratives while exercising minimum guidance and interference during the interviews and focus groups. As a counsellor, I am trained in the person-centred model focusing on the principles of empathy, congruence and unconditional positive regard. These elements could create such an environment that the participants would feel safe and be encouraged to share their stories.

Furthermore, prior experience of conducting focus groups would have helped me navigate and facilitate the discussions, as there is always the possibility that participants could deviate from the main topic. All these previous experiences and skills have strengthened my confidence in my abilities and my trust in the dynamics of qualitative research, therefore allowing me to immerse myself in that process and embrace the fluidity that often characterizes it.

Although, my own experiences could have provided me with a strong advantage, they could also put me in disadvantaged position in some respects. It could have been hard to listen to my participants talk about their experiences of ASDs without trying to develop a more clinical understanding. I may also had to fight the need to provide emotional support. Since this was an exploratory study, having no prior experience regarding ASDs could have made it more challenging for me to focus the discussion on aspects that were important for the research questions.

It was crucial to balance the freedom allowed to the participants in the context of the interviews and focus groups with the need to acquire information pertinent to my research questions. Familiarity with qualitative research could have reduced the urgency to plan ahead and consider any possible obstacles that could occur during an interview and focus group. Cultural differences could also have been a source of potential influence. My experiences of schooling and support in my country could have colored the way in which I perceived the experiences of my participants. Therefore, it was crucial to be aware of all these possibilities while I was conducting my research.

In sharp contrast with the qualitative paradigm the underlying philosophy behind quantitative inquiry is that a knowable, single reality exists. Behaviour is controlled by cause-effect variables and can be studied by detached and objective scientists. The aim of a quantitative research study is to arrive at verified hypotheses established as facts or laws (Lyncoln & Cuba, 2002). In this context the research starts by making claims and then continue by refining or abandoning some of them for others most strongly warranted.

In order to achieve this the researcher tries through reduction to arrive to a set of variables tightly controlled, through design or statistical analysis, so that they can provide measures or observations for testing a theory (Creswell, 2003). Researchers seek to develop relevant true statements that can describe the situation that is of concern or the relationships of interest. Being objective is an essential aspect of the research and for that reason researchers must examine methods and conclusions for bias (Creswell, 2003).

3.4 Choosing the pragmatic approach and the mixed methods design

The pragmatic approach to research accepts that there are philosophical differences between the two paradigms. However, it suggests that their philosophical underpinnings are independent from the methods, which can be used together to provide the most appropriate combination to answer a specific research question (Green & Carecelli, 1997). This approach respects the viewpoints of these two paradigms while also seeking a workable middle solution where a methodology is chosen for its aptness for answering specific research problems (Johnson, Onwuegbuzie, & Turner, 2007; Glogowska, 2015).

According to Hammersley (2000), in research practice we are not actually faced with two traditions that are internally coherent and based upon opposed philosophical views. In fact, there is a variety of techniques for data collection and analysis and there is no fixed relationship between particular philosophical views and the use of particular methods. Selection among these methods depends upon the situation and purpose of the research, rather than on a commitment to one or another philosophical view of the world and the nature of inquiry.

This study employed a mixed methods research design that involved collecting and combining both qualitative and quantitative data. This research design can serve many functions (e.g. triangulation; exploration; validation) and can occur at many stages of the research (e.g. question formulation; data collection; data analysis or data interpretation) (Bryman, 2006a). Finally, the mixed methods approach can also result in a more comprehensive understanding of a research problem compared to relying exclusively to either qualitative or quantitative data. (Bryman, 2006a; Creswell, 2003; O' Cathain, Murphy, & Nicholl, 2007). This is often being referred to as “complementarity” (Glogowska, 2015) or “completeness” (Bryman, 2006a).

Qualitative methods (interview, focus groups) were used to explore views, needs and experiences among young people with ASDs, their parents and education providers. The use of the quantitative method (cross-sectional survey) aimed primarily to provide meaningful comparisons between different sections of the populations under study, which would not have been possible if relying solely on a qualitative approach. Different methods were combined in two phases. During data collection, where main findings from the two qualitative studies informed the design of the survey and during data interpretation, where findings from all three studies were brought together and discussed.

3.5 Study Methodology

This study included three research phases with each one of them employing a distinct design and methodology:

1. Semi-structured interviews (April 2016-September 2016).
2. Focus groups (December 2016-October 2017).
3. Cross-sectional survey (November 2017-April 2018).

Although there was not any interdependence among the two qualitative studies the design of the survey was based on their combined findings. The following sections of this chapter describe the rationale behind the use of each method.

3.5.1 Interviews

The first study aimed to provide a deep understanding of participants' experiences, views, aspirations, and needs. Therefore, a choice had to be made between interviews and focus groups, based on which the most appropriate method was to answer the research questions. One of the benefits of interviews is the richness of data they can produce (Harvey-Jordan & Long, 2001). It could be difficult to elicit experiential narratives from focus groups and they are more likely to give rise to attitudes, opinions and third person stories (Smith, Flowers, & Larkin, 2009).

Furthermore, focus groups are not recommended in cases where participants are not comfortable with each other and will be discouraged from openly discussing their feelings and opinions (Morgan & Krueger, 1993). A focus group may have been a particularly challenging experience for young people with ASDs. During the focus group they would have been asked to engage in a discussion not only with the researcher but also with other young people with whom they would not be familiar. This could have induced more anxiety and may have affected participation.

Semi-structured interviews were used to obtain the views and experiences of both young people with ASDs and their parents regarding life skills training they have received, along with their aspirations and needs for future training. Interviews are considered an appropriate method for investigating the experiences of parents and young people with ASDs and have been extensively used in literature (Cheak-Zamora et al., 2015; Bottema-Beutel, Mullins,Harvey, Gustafson, & Carter, 2015; Humphrey & Lewis, 2008; Preece & Jordan, 2010).

Semi-structured interviews were chosen over fully structured. Semi-structured interviews are generally organised around a set of predetermined open-ended questions while a number of other questions are emerging from the dialogue between interviewer and interviewee. This format allows the interviewer to explore in depth social and personal matters while additional questions can elicit more detailed narratives and stories (DiCicco-Bloom & Crabtree, 2006).

Although semi-structured interviews were considered the most appropriate method for this phase of data collection they had one potential disadvantage. One of the possible limitations is that the researcher may introduce his/her bias in the framing of the questions and in the interpretation of responses (Kumar, 2005). Keeping a reflective diary throughout the process and monitoring reactions could minimize this possibility.

3.5.2 Focus groups

The aim of the second study was to investigate life skills training and support that is available in schools along with the views of education providers regarding the current provisions and their recommendations for improvements. For this study three data collection methods were considered: interviews, focus groups and ethnography.

Ethnography can be defined as the study of social interactions, behaviours, and perceptions that can be found within groups, teams, organisations, and communities. During ethnographic research, the researcher observes or interacts with participants in their environment (Reeves, Kuper, & Hodges, 2008). Limited information on how life skills training was being delivered within schools and the time constraints of the PhD would have made it difficult to use this method. It would not have been possible to determine how long observations will need to take place or over what periods of time.

Failure to observe all aspects of life skills provision could have resulted in somewhat fragmented and limited understanding. Since it was not possible to know how and where the training takes place (e.g. within classroom; one to one sessions), there were additional concerns regarding the presence of an external observer during the training sessions and whether this would be welcomed and appropriate.

Taking this into account, ethnography was not considered as an appropriate methodology in this instance. A choice had to be made between interviews and focus groups. The aim of the study was to capture views and experiences related to education providers' professional life. Therefore, a group discussion could elicit more views and ideas in comparison to interviews, as it could generate a meaningful interaction between participants. Gaining a better, holistic understanding of the life skills training and support offered in each school could be benefited by the high variability of participants. They could share their different experiences which have acquired as a result of their different roles.

As focus groups allow increased interaction between participants, their discussions may reveal a range of topics that would have not been anticipated otherwise. More to that, it could have been easier to access more schools in a shorter period of time, as at least one focus group in each would be sufficient, and this would have increased the variability of the data.

Focus groups are also part of the phenomenological tradition. They involve one or more discussions with participants who focus collectively on a topic selected by the researcher and presented to them most commonly as a set of questions (Wilkinson,1998). Krueger and Casey (2000) advise that focus groups should be conducted several times with similar types of participants as this will allow the researcher to identify trends and patterns.

Focus groups are also distinguished from group interviews by the use of group interaction in order to generate data (Kitzinger, 1994). They are considered an appropriate method of data collection when the purpose of the research is to elicit people's understandings, opinions and views (Wilkinson, 1998). They have also been used extensively in eliciting the views of education providers (Athanases & Oliveira, 2008; Boardman et al., 2005; Schetzina et al., 2009).

It could be argued that the focus group is not the most appropriate method for acquiring in depth information in comparison to one to one interview (Krueger & Casey, 2000). However, it cannot be assumed that focus groups will discourage participants from sharing personal views. They can include individuals who are less reserved and more eager to break the ice and talk about more taboo issues, therefore encouraging others to take part in the discussion and disclose (Kitzinger, 1994). Another possible limitation is that the researcher may introduce his/her bias in the framing of the questions and in the interpretation of responses (Kumar, 2005). Keeping a reflective diary throughout the process and monitoring reactions could minimize this possibility.

3.5.3 Cross-sectional survey

The aim of the third study was to investigate and compare the views and experiences of the parents whose children attend various types of school and the education providers who work at similar establishments. Quantitative methodology was considered most appropriate for the aims of this study. Surveys provide a numeric or quantitative description of opinions or attitudes of a population by using questionnaires or structured interviews for data collection. Their aim is to generalize from a sample to a population so that inferences can be made about some characteristic, attitude or behavior of this population (Creswell, 2003).

One of the main disadvantages of surveys is that they are inflexible, since participants have to choose mainly from close ended or fixed responses. At the same time this inflexibility is also an advantage as it enables comparisons across participants. However, this requires a deep understanding of the important questions to ask and the range of possible responses.

Two questionnaires were designed, one for parents and one for education providers. These questionnaires were based on the findings of the two previous qualitative studies. Questionnaires are considered an appropriate method for gathering information from a large sample (Lorelle Frazer & Lawley, 2000) and have been applied in studies investigating the views of parents, professionals and individuals with ASDs (Callahan et al., 2008; Barnard et al., 2000).

3.6 Validity and reliability in qualitative research

Issues around validity and reliability in qualitative research along with the notion of generalizability constitute the concept of quality of research. Validity and reliability are highly connected, and it is not considered possible to have one without the other (Lyncoln & Cuba, 2002). Since phenomenology rejects the assumption of the reality being independent of our perception of it, we cannot establish the truth of an inquiry referring to an external reality. As a result, alternative procedures have been suggested in order to evaluate the finished product of the qualitative research.

3.6.1 Internal validity

In qualitative research validity refers to whether a particular methodology is appropriate for the chosen topic of inquiry and is also related to the procedures that are being used by the researchers (Kuzmanic, 2009). There are several criteria that can be applied in order to establish validity in qualitative research (Leung, 2015). The researchers need to determine that:

1. The research question is appropriate for the desired outcome.
2. Methodology and processes are appropriate for answering the chosen research question.
3. The design is appropriate for the methodology.
4. Sampling and data analysis meet the aims and methods of the study.

5. Results and conclusions are valid for the sample and context

The literature review and the conclusions drawn from the critical evaluation of previous studies informed the research questions. The rationale behind the choice of the mixed methods design has been presented in the beginning of this chapter along with further detailed accounts discussing the choice of each research method (interviews; focus groups; cross-sectional survey). Data analysis and sampling methods are also discussed, and details are provided in the Chapters 4,5 and 6. Finally, the process of triangulation, which will be explained under reliability, can assist in establishing the validity of results and conclusions for the sample and context.

3.6.2 Reliability

In quantitative research reliability refers to the extent to which studies can be replicated while using the same methods and processes and obtaining the same results. However, such a definition cannot be applied in a meaningful way in qualitative research and therefore reliability has become synonymous with consistency (Leung, 2015). Establishing consistency requires from researchers to allow others to judge the quality of their work, resulting in having an obligation to report sufficient details of the methods used for data collection and analysis.

Furthermore, there are additional elements that researchers can incorporate in their analysis and reporting in order to enhance the quality of their report. Examples are instances of refutational analysis and the inclusion of contradictory cases, constant data comparison, comprehensive use of data, use of tables and triangulation (Leung, 2015; Patton, 1999). There are various forms of triangulation and analyst triangulation, which involves using multiple analysts to review the findings (Patton, 1999) was utilized. Data were triangulated with one member of the supervisory team. The researcher, along with the primary supervisor discussed the textual data and agreement was reached between the two before finalizing the themes and sub-themes. Themes and sub-themes were also peer reviewed by the whole supervisory team.

Additionally, the final quantitative study served as another form of triangulation. The questionnaires which were utilized during the final study reflected the main findings of the two qualitative studies, therefore serving as a form of methodological triangulation. Although this was not the main aim behind the choice of the mixed methods approach, the quantitative study helped to increase the validity and consistency of the findings.

A useful tool that could contribute towards a more comprehensive analysis and greater consistency is NVivo, a software designed for deep levels of analysis for small or large volumes of qualitative data (Bergin, 2011). NVivo could help the researchers overcome some of the so called “deficiencies of the analyst” that can potentially interfere and obstruct the analysis. Example can be the tendency to ignore references that are contradicting with beliefs and views already held and the tendency to discount new or unusual information (Robson, 2002).

NVivo relies on the creation of nodes, with a node being a collection of quotes and references about a specific theme. This process is encouraged very early in the analysis, even before the analyst has the opportunity to formulate concrete ideas about the data. Therefore, the analysis can be more driven by the data than driven by any conceptions and understandings held by the analyst.

This advantage of NVivo can also become one of its main drawbacks. It can potentially lead to a more literal analysis of the data since it encourages an early categorization into nodes along the possibility of the analyst becoming more focused on the mechanistic aspects of analysis (Bergin, 2011). In the chapters 4 and 5, which describe the two qualitative studies, I tried to report faithfully and in great detail the process of data collection and to be transparent about my analysis. I included tables, extensive discussion of themes and sub-themes, and numerous direct quotes from participants to allow the reader to gain a better understanding of the findings and my interpretations.

3.6.3 Generalizability-external validity

Another issue that can be a cause of controversy in qualitative research, when it is compared to quantitative paradigm, is the generalization of the results (Krueger & Casey, 2000). It can be argued that qualitative research does not aim to generalize but to arrive to an understanding about how the world is constructed from the perspective of research participants. What it has been suggested instead is the concept of transferability, parallel to generalizability (Krueger & Casey, 2000; Malterud, 2001).

In this case is the receiver who decides if the results can be applied to the next situation based on similarities between the time, place, people and other social contexts (Krueger & Casey, 2000; Leung, 2015). Providing adequate information about the participants, the location and time of the study and background details will allow others to judge whether there are enough similarities so that the results can be generalized (Leung, 2015).

3.7 Validity and reliability of quantitative research

If we could summarize the overall common aims of the three studies these were to capture views and experiences among parents, young people and education providers regarding life skills provision and types of training that they consider beneficial. Within this context the main aim of the final quantitative study was to enable meaningful comparisons between different groups of participants, which would not have been possible if relying solely on the two qualitative studies.

Therefore, the whole investigation was operating within a qualitative research framework. According to Bryman (2006$_b$) in a mixed methods design, when the amount of quantitative data is minimal within a predominantly qualitative project, criteria associated with the evaluation of qualitative research could be more appropriate than either separate or bespoke criteria. The concepts of validity and reliability will be discussed in relation to the specific aims of the final study and in connection with the qualitative studies that preceded.

3.7.1 Validity

Following from the initial qualitative studies the questionnaires continued the exploration of training needs and current experiences of life skills training and support. The items in the questionnaires were developed based on previous empirical work, interviews with young people with ASDs and their parents and focus groups with education providers. Qualitative analysis of interviews and focus groups provided the main findings which were used in the design of the questionnaires.

Concrete examples and further details of this process are provided in Chapter 6 which describes the design of the questionnaires. Furthermore, participants were asked to complete a social validity form where they had the opportunity to comment on the content and appearance of the questionnaires in order to establish whether they captured most of their experiences and views.

3.7.2 Reliability

The aim of this study was not to generalize but instead to allow meaningful comparisons between different groups of participants and continue the exploration of qualitative findings. Furthermore, this was a quantitative study based on the findings of two qualitative studies. As a result, it would not have been possible to make any claims of generalization to a larger population before more replications have taken place.

Since the concept of generalizability is not applicable, the concept of consistency as described in the qualitative paradigm was considered more suitable. The process of creating the questionnaires is explained in Chapter 6, where also characteristics of the sample are adequately described and data analysis procedures along with findings are reported in great detail.

3.8 Ethical Considerations

Three separate ethics applications were developed one for each phase of data collection. Each application included:

1. Description of rationale, aims and methods of each study.
2. Ethical considerations relevant to each study.
3. Description of recruitment procedures.
4. Documentation (Invitation/Letters and Consent Forms) that was used in the recruitment of research participants.

These applications were submitted to the Medway School of Pharmacy Research Ethics Committee and approval was granted before commencing each phase of data collection. Ethical issues pertinent to each study are further explored in the following chapters.

3.9 Rationale for next chapter

The three studies of this thesis are presented in chapters 4, 5, and 6. The initial qualitative exploration focused on the views and experiences among young people with ASDs and their parents regarding current life skills provision and their aspirations and needs for future training.

Chapter 4 : Interviews

4.1 Chapter summary

Background: High functioning individuals with ASDs have poorer life skills than expected based on their cognitive abilities. They are also less likely to have access to support after they exit educational provisions, compared to individuals with ASDs and intellectual disability. Therefore, providing life skills training within schools can contribute towards improving adult functioning. Furthermore, individuals with ASDs and their families should be given the opportunity to voice their own needs and views about interventions directed at them. This was a qualitative study with the aim to investigate: **a)** views and needs in relation to adulthood transition as expressed by young people with ASDs and their parents; **b)** their experiences of previously accessed life skills training and support, with an emphasis on school provision; **c)** what type(s) of future life skills support they may consider beneficial and would wish to access.

Method: Data were collected through 20 semi-structured interviews with 10 young people in the age groups 11-17 years and 10 mothers. Data were analysed using Thematic Analysis.

Results: Perceived inability from schools and also external services to recognize and manage individual needs was the main cause for dissatisfaction among participants. Participants not only expressed a desire for personalized life skills support but also considered mentoring/befriending to best meet this requirement. More to that, they voiced a need for the support to be delivered within schools. However, only two of the young people were receiving ongoing support around life skills from their perspective schools. Mothers also wanted to take a step back from supporting the young people and allow them more independence.

Conclusion: The study highlights possible issues in the provision of life skills support from the perspective of young people and their parents. It also provides new insights regarding the types of support that they consider desirable and offers suggestions for the design of future interventions. Recommendations for schools and services are also being discussed.

4.2 Introduction

Although various educational placements exist for young people with ASDs, UK government legislation over the past two decades (Wilkinson & Twist, 2010) has placed focus on inclusive education through mainstreams schools where all pupils with disabilities will, in theory, be provided for. Indeed, 70% of pupils with ASDs attend mainstream schools (DfE,2014$_a$). Their needs have increasingly come to the fore, especially due to the difficulties that have sometimes arisen around inclusion and support. Studies have explored several issues highlighted by both pupils and parents, including peer-relationships (Carrington & Graham, 2001; Reid & Batten, 2006), communication between schools and parents (Dillon & Underwood, 2012), and lack of training among school staff (Dillon & Underwood, 2012).

It is widely acknowledged that peer-support is an integral part of the overall school experience and can be utilized to increase social interaction skills of pupils with ASDs and facilitate their inclusion in mainstream schools (Dillon & Underwood, 2012; Harrower & Dunlap, 2001; Humphrey & Lewis, 2008). Positive experiences with peers and perceived social acceptance contribute towards better adaptation (Vernberg,1990).

Pupils who describe having satisfactory friendships show more involvement in classroom activities along with appropriate classroom behaviour (Berndt & Keefe, 1995). Additionally, peer-relationships can influence adult outcomes as peer rejection and absence of friendships are linked with less positive perceptions of personal confidence and self-worth and more severe psychopathological symptoms (Bagwell, Newcomb, & Bukwoski,1998). However, young people with ASDs who attend mainstream schools face significant challenges in their relationships with their peers (Reid & Batten, 2006; Locke, Ishijima, Kasari, & London, 2010).

They can have the social desire for peer involvement and relationships (Bauminger & Kasari, 2000; Jones & Meldal, 2001) and although may not always appear isolated in the school environment their peer acceptance is low (Chamberlain, Kasari, & Rotheram-Fuller, 2007). Their difficulties around social interaction and communication make it hard for them to relate to their peers and develop friendships. They report fewer friendships compared to the general population and to their peers with SEN without an ASD (Rowely et al., 2012). They also rate the quality of their friendships lower in terms of companionship, security/trust, and helpfulness than their typically developing peers (Bauminger & Kasari, 2000; Locke et al., 2010).

Pupils with ASDs can perform academically, however they do not feel able to fit in and this can lead to bullying, isolation, loneliness and few close and confiding friendships, thus making school an unpleasant experience (Humphrey & Symes, 2010; Portway & Johnson, 2005). Furthermore, pupils can be aware of their own difficulties (Jones & Meldal, 2001) and often try to masquerade and hide them in an attempt to conform to social rules and to not appear different from their peers. These attempts are not always successful and can result in heavy emotional and psychological distress when the school day is over (Carrington & Graham, 2001).

Communication between schools and parents can also be perceived as problematic with parents believing that schools are not always able to find that right balance between too little or too much communication (Dillon & Underwood, 2012). On the one hand, there are parents who do not feel able to pass on information to schools or do not feel confident and reassured that such information is being used productively (Dillon & Underwood, 2012). On the other hand, some parents report high levels of communication and as a result, problems at school are being fed back home at a time when they want to distance themselves from schools (Dillon & Underwood, 2012). Another issue is the perceived lack of consistency regarding training and awareness among many education providers. Parents believe that understanding of ASDs needs to run through the whole school and encompass each and every member of staff (Brewin, Renwick, & Fudge Schormans, 2008; Dillon & Underwood, 2012). Failure even from one individual to appreciate the specific needs of these pupils can have a detrimental impact (Brewin, Renwick, & Fudge Schormans, 2008; Dillon & Underwood, 2012).

Few studies have investigated the views of parents and young people with ASDs regarding the types of support considered to be beneficial. In Tobias (2009) parents and pupils with ASDs believed that school mentors would be helpful for discussing a variety of issues with the pupils, favoured personalised support and wanted schools to include the teaching of practical skills. According to a recent study in Canada parents sought training programs on social competence that were customized for their children and believed that one to one support was better suited for individualized instruction (MacCormack, 2017). Parents have also stressed the importance of socialization programs and noticed that, although good programs are available for younger children, there were fewer opportunities for adolescents (Cheak-Zamora et al., 2015).

As young people with ASDs grow older and progress through the educational system they need to make additional preparations for adulthood transition (Seltzer et al., 2003). Transitioning from school into the adult world is a difficult process for every adolescent. It involves negotiating and managing new living arrangements, romantic relationships, family relationships and changes in the domains of education and work (Arnett, 2000). Individuals with disabilities, including those with ASDs and their families, face additional obstacles as they must go through three distinct transitions: status transitions (e.g. getting a job); family life transitions (e.g. new daily family routines) and also bureaucratic transitions (e.g. moving to adult services) (Blacher, 2001).

Young people with ASDs are concerned about adulthood. Studies have documented that their concerns can focus on every day activities such as driving, maintaining hygiene, cooking to more demanding and complex situations such as education, work, friendships and support systems (Cheak-Zamora, Teti, & Maurer-Batjer, 2018). Worries around money management and financial skills are also prevalent (Cheak-Zamora, Teti, Peters, & Maurer-Batjer, 2017).

According to Shattuck, Orsmond, Wagner, and Cooper (2011) once young people with ASDs exit school provisions, there is a steep decline in the received services (medical; mental health; speech therapy; case management). Parents have also noted a lack of guidance regarding the transition from childhood to adulthood and inadequate support in schools (Portway & Johnson, 2005). Without support from school, family becomes responsible for finding, organising, and maintaining services and educational or employment activities for the young people with ASDs (Smith & Anderson, 2014), which can result in a high level of caregiver burden (Cadman et al., 2012; Cheak-Zamora et al., 2015).

4.3 Research aims

A limited number of qualitative studies have investigated the experiences and views of young people with ASDs and their parents in relation to non-academic support they are receiving from schools and other services. MacCormack (2017) researched the needs of parents and young people regarding social competence programs in Canada and Tobias (2009) looked into perceptions of general support offered in one mainstream secondary school in the UK. Concerns and needs in relation to adulthood transition were explored in a series of studies (Cheak-Zamora et al., 2015; Cheak-Zamora et al., 2017; Cheak-Zamora et al., 2018) all of which were conducted in the US.

This qualitative study focuses specifically on the experiences of high functioning young people with ASDs and their parents in relation to life skills support they have received from schools and services and also their needs for future training. The study aimed to investigate:

1. Views and needs in relation to adulthood transition as expressed by young people with ASDs and their parents.
2. Their experiences of previously accessed training and support, with an emphasis on school provision.
3. What type(s) of life skills support they may consider beneficial and would wish to access.

4.4 Method

4.4.1 Sampling method and inclusion/exclusion criteria

A purposive sampling method was used to recruit a sample that shared common characteristics and could provide greater insights into the research questions (Devers & Frankel, 2000).

Inclusion criteria

In order to be included in the study participants had to meet all of the following inclusion criteria:

Young people:

- Have a diagnosis of Autism, AS or PDD-NOS.
- In the age groups 11-21 years.
- No intellectual disability.
- Attending or have attended a secondary educational setting that also caters for pupils with no global learning disability.
- Good verbal ability.
- Fluent in English.

Parents/legal guardians:

- Have child/ren who meet the inclusion criteria.
- Fluent in English.

Exclusion criteria

Participants were excluded from the study if they met at least one of the following exclusion criteria:

Young people:

- Do not have a diagnosis of Autism, AS or PDD-NOS.
- Below the age of 11.
- Above the age of 21.
- Intellectual Disability.
- Attending or have attended a secondary educational setting that only caters for pupils with global learning disability.

- Limited verbal ability/nonverbal.
- Not fluent in English.

Parents/Legal guardians:

- Have child/ren who do not meet the inclusion criteria.
- Not fluent in English.

4.4.2 Recruitment

Ethical Approval for the study was obtained from the Medway School of Pharmacy Research Ethics Committee (Appendix B_1). Two autism charities based in Kent acted as gatekeepers for the study. The gatekeepers received an Information Letter about the study (Appendix B_2) and were requested to sign a Consent Form (Appendix B_3).

The gatekeepers e-mailed an Invitation Letter (Appendix B_4) to all parents who were their members. The aim was to recruit both the parent and the young person. Potential participants were requested to contact the researcher, via e-mail or telephone both of which were available on the Invitation Letter, who provided them with Information Letters and Consent/Assent Forms. Parents were requested to confirm in writing that young people met all the inclusion criteria.

4.4.3 Ethical Considerations

Ethical issues, particularly relevant in qualitative research, were considered with guidance from Houghton et al. (2010). The main ethical considerations for this study were use of incentives, the process of acquiring informed consent, maintaining confidentiality, avoidance of harm, and potential safe guarding issues.

Incentives

Gatekeepers received £400 each as compensation to cover man-power expended on facilitating the project and use of premises. Parents were offered a £25 LovetoShop voucher and young people were offered a £10 AMAZON voucher as incentives for participation. The use of financial incentives in research is considered controversial. Incentives may improve recruitment (Bernstein & Feldman, 2015) and when applied correctly could serve as an acknowledgement of participants' time and effort (Groth, 2010).

The downside is that they could be coercive, especially for people who have limited financial resources (Groth, 2010), and this raises several additional concerns. They may provide motivation for fabricating information in the interview to gain the money and motivate participation in an interview with a topic that may elicit distress (Robinson, 2014). A number of safeguards were put in place in order to avoid the above risks. The financial incentives offered to the participants were kept to a minimum and the use of gatekeepers provided assurances that participants: a) were affected by the issues investigated in this study and b) had a genuine interest and desire in sharing their views and experiences.

Informed consent

Houghton et al*.* (2010) stress the importance of 'informed process consent" in qualitative research, where the issue of consent needs to be revisited at various stages of the research process, given that the experience of being interviewed might be unpredictable. Participants were reminded of their right to withdraw at any time during the interviews and in cases of any noticed distress their consent was sought again.

Different Information Letters and Consent/Assent Forms were developed for the different age groups to reflect their different level of understanding and ability to provide informed consent. Information Letters (Appendixes B_5 & B_6) which were provided to participants before the interview, included information about the research, what it would involve, potential risks, and proposed methods of dissemination.

Participants who were able to consent for themselves, parents and young people aged 16 years and above, were asked to sign a Consent Form (Appendix B_7). Young people in the age groups 11-15 years were not considered able to give informed consent thus, their parents received a Parental Request Letter (Appendix B_8) and both a Parental Consent Form (Appendix B_9) and an Assent Form (Appendix B_{10}) were required in order to be included in the study. The Assent Form was completed by the young people and their parents signed the Consent Form.

The researcher used a structured approach, as advocated by the British Medical Association, with the age groups 16-21 years to assess their capacity for providing informed consent (www.bma.org.uk). Before commencing the interview, the researcher went through the Information Letter with the young people and answered any questions they had. Every effort was made by the researcher to assist all young people to understand what the study would involve for them. Immediately afterwards, a set of questions were asked to young people to assess their capacity to give informed consent:

- Do you have to take part in this study, or is it OK to say ‘no’?
- Can you tell me what you would do in this study?
- Can you tell me the main risks of this study?
- Can you tell me the benefits of this study?
- Considering what is good and what is not so good about taking part in the study, would you like to take part in this study?

If young people answered satisfactorily the above questions, then they were supported to complete the consent form. If they couldn’t answer one or more of the questions, then they were withdrawn from the study. If the researcher was unsure whether their answers reflected an understanding of the study, then they were withdrawn.

The aim of this assessment was to ensure that young people understood what was required from them and what the study would involve and therefore were able to make an informed decision about whether they wanted to participate or not. If young people were considered as not having the capacity to provide informed consent, they still received a £10 Amazon voucher.

Confidentiality

From the onset of the study, it was made clear to participants that interviews would be audio recorded and that any identifiable personal information would be stored securely. Audio recordings were erased after they had been transcribed and analysed. Transcripts were fully anonymized, and names of local services were replaced with a unique identifier (e.g. Service A) and used consistently between transcripts. Names of schools and geographical areas were removed.

Avoidance of harm

During the interviews young people and their parents were discussing their experiences of living with ASDs and their needs, expectations and concerns for the future. There was a possibility that the nature of the subject may give rise to feelings of distress and anxiety amongst participants. This acknowledgement resulted in the inclusion of relevant statements in the Information Letters to warn participants of possible adverse effects. It was also made clear to the participants that: **a)** all their responses would be anonymous; **b)** participation is voluntary.

When participants became visibly upset during the interview the researcher used her clinical skills and experience to appropriately handle the situation. The researcher immediately paused the interview, allowing participants sufficient time to take a break and recover. There was also the option to spread the interview over more than one session if the participant did not feel able to continue. Their consent was sought again before continuing with the interview. Participants were also advised to contact the charities that acted as gatekeepers for the study, as they were considered to be in the best position to provide advice and further support.

Safeguarding issues

There was a small possibility that disclosures of abuse or other illegal acts could take place, although this was not the focus of the interviews. This acknowledgement resulted in the inclusion of relevant statements in the Information Letters which clarified that the researcher will be required to break confidentiality and inform statutory agencies where abuse or another illegal act was disclosed.

4.4.4 Reflexivity

Although I familiarized myself with the literature before commencing the study, I had no previous research, clinical or personal involvement with the specific population. Therefore, I held no strong opinions and views. Most of the interviews were conducted within two weeks allowing limited time for reflection. During this short period, I was trying to monitor my reactions and feelings to ensure that these did not influence my role as a researcher.

I also made efforts to gradually improve the process of data collection. After each interview notes were taken which included my thoughts on what I believed had gone well or could have gone better, obstacles that I encountered and any other thoughts or feelings that were occurring to me. These notes also included comments that parents or young people made before and after their interviews, and in some cases, initial themes that seemed to be emerging. They were also used to shape my questions for the next interview.

Extract from reflective diary.

The second and third interviews with a mother and her 14- year- old son took place during the summer break. The setting of the interview was the living room of the family house. The young person was happy to be interviewed on his own. He also made small chat with me before the interview, asking how my trip was and if I had any difficulty finding the house. His attitude made me feel more relaxed, as I thought that we were going to have a nice discussion.

He had printed all the paperwork, which I found quite impressive. We sat opposite each other having the recorders placed on a small coffee table in the middle. I asked him if he was ok with me recording the interview. He wasn’t nervous- at least visibly- and he talked extensively about his interests, various activities and future plans. He highlighted the importance of peer support and meeting other people with ASDs within his school’s “ASD department”. This was the first time that a parent or young person highlighted this aspect. He was also the first young person so far to talk openly about his diagnosis. I wondered if this openness was somehow linked to his comments about peer support. He was very articulate and able to talk about what forms of support he finds useful. The young person stepped out of the room when I interviewed the mother. Mother sat closer to me in a chair next to my sofa. Mother talked specifically about her own efforts to support him and prepare him for adulthood. She had a real sense of achievement and she was satisfied with the progress of her son. However, she highlighted that her own professional role as a teacher and the assistance she had from colleagues was of great help and that not every parent would be able to offer the same level of support. Around twenty minutes into the interview the bell rang and someone brought in a fridge. The interruption lasted around twenty minutes. It took a while to get back on track with the interview. After the interview finished, the mother expressed her gratitude that someone is actually focusing on young people who are on the high functioning end of the spectrum. Invitations for research that she usually receives are in regards to lower functioning adolescents. I felt that the interviews went well, although the mother needed frequent prompting to discuss issues in more detail. So far, mothers were usually able to talk about various topics extensively without my interference. Therefore, I need to be more prepared for this possibility in the future and not be taken by surprise when I need to ask more questions in order to facilitate the interview.

4.4.5 Data Collection

4.4.5.1 Interviews

Data were collected through semi-structured interviews. All interviews were conducted by Sofia Chantziara. Taking into consideration the time constrains and the limited resources available, the maximum number of interviews for this study was set to 25. The aim was to interview young people and their parents separately. Participants were offered the choice to be interviewed either in their own home, in the premises of the study's gatekeepers or in Medway School of Pharmacy.

It was acknowledged that the interview process could make young people feel anxious and potentially discourage them from taking part in the study. In order to overcome this potential obstacle, young people in the age groups 11-15 years were offered the additional option to conduct interviews using Skype, phone or instant messaging (Skype/e-mails). These options were not available for young people in the age groups 16-21 years as the researcher needed to verify their capacity to provide informed consent and this was only possible in person. Offering electronic options instead of face to face interviewing is considered a suitable approach in order to capture the views of young people with ASDs (Benford & Standen, 2011; Bottema-Beutel, Mullins, Harvey, Gustafson, & Carter, 2015). It was expected that any feelings of anxiety could be alleviated by removing the personal contact with the researcher.

4.4.5.2 Materials

Different questions guides were developed for young people and their parents. Structure and content of the interview differed between the two groups in order to reflect their different needs and developmental level. The question guide designed for the young people opened with a discussion about their hobbies and interests to make them feel more comfortable and relaxed.

This first part of the interview also enabled the researcher to develop a rapport with the participants, especially those in the younger age groups. The guide did not include direct questions regarding life skills challenges as shifting the focus on difficulties could have caused unnecessary distress to the young people. Instead, the aim was to encourage them to talk about various aspects of everyday functioning and to give them the opportunity to identify and discuss their difficulties and concerns.

The wide age range of the participants (11 to 21 years) called for more concrete and simplified questions that would primarily correspond to the needs of the younger age groups. With older participants however, it was possible to follow up on certain points they raised, ask more sophisticated questions and focus more on certain areas.

The topic guides were developed following recommendations from Smith and Osborne (2015) and were revised through discussion with the supervisory team. Questions reflected the overall area of the interviews and the broad range of issues to be covered. They also included, various possible prompts and probes which could follow from possible answers. In general, it is recommended to keep more personal and sensitive questions for the end.

Nevertheless, the parents were asked at a very early stage in the interview to share information about their children. This was important, since every young person has a very unique set of needs which were necessary to be captured in advance in order to acquire an understanding of participants views and experiences. Furthermore, participants were already aware about the personal nature of the interviews from the Information Letters they had received.

The guides were pilot tested with a group of researchers who had experience of conducting interviews with vulnerable populations. The first two interviews were also treated as pilot interviews to validate and enhance the clarity of the topic guide. The open questions worked quite well with the participants and it was not necessary to change the topic guides. Therefore, the two initial interviews that were treated as pilot interviews were included in the analysis. Although, the initial topic guides were highly structured their constant revision resulted in keeping only a small number of questions to guide the discussion towards the end of the data collection phase. This refinement reflected two developments:

- Researcher's increased confidence with the interview process. This led to the growing use of appropriate prompts in each interview to explore different areas of the participants' responses, rather than following closely the topic guides

- Participants' ability and willingness to engage with the topic. This gave them the leading role during the interviews with the researcher following their narratives instead of structuring and guiding the discussion with frequent questions.

Initial topic guides

Young People

1. What are you favourite subjects/activities?
   - Extra-curricular activities (sports/music)
2. How are things at school?
   - Relationships with teachers
   - Relationships with peers
3. What do you want to do after you leave school?
4. What are the difficulties that you may face?
5. What support would you like while you are growing up and you are going through secondary school?
   - Current Support (school/other services)
   - Positive/negative experiences

Parents

1. Tell me about your child
   - Diagnosis
   - Age of Diagnosis
   - Current life skills difficulties
2. What are your future aspirations for you child?
3. Which are the areas that you feel that you/ your child struggles /will struggle with?
4. What types of life skills support are/will be available for you and your child?
   - Support from school-positive/negative experiences
   - Support from other services-positive/negative experiences
5. What would you like to be included in a life skills intervention?
   - Parental involvement
   - Parental training

Revised topic guides

Young people

1. What are you favourite subjects/activities?
2. How are things at school?
3. What do you want to do after you leave school?
4. What are the difficulties that you may face?
5. What support would you like while you are growing up and you are going through secondary school?

Parents

1. Tell me about your child
   - Diagnosis
   - Age of Diagnosis
2. What are your future aspirations for your child?
3. What types of life skills support are/will be available for your child?
4. What would you like to be included in a life skills intervention?

The researcher would terminate the interview when it was judged to have come to a natural conclusion. At this point, one additional question was asked to give participants the opportunity to add anything else they wished to say. Interviews were audio recorded with the consent of the participants

4.4.5.3 Participants

Information Letters and Consent/Assent Forms were distributed to 37 parents who had contacted the researcher expressing an interest to participate. Out of them 27 made no further contact with the researcher and did not reply to a reminder e-mail which was send to them. The study included 20 participants broken down to 10 young people and 10 mothers, 9 of which were the mothers of these young people. One mother participated with her two children. The daughter of one mother was unable to take part due to severe anxiety. None of the young people was withdrawn from the study on the grounds of lacking capacity to consent. Two of the young people who were over the age of 16 were assessed by the researcher and they were both considered able to provide Informed Consent.

Mothers confirmed in writing that young people had a formal diagnosis from a Psychologist, Psychiatrist or Paediatrician and they met all the remaining inclusion criteria. The characteristics of participants are presented in Table 7 and Table 8. The young people were in the age groups 11-17 years. Nine of them were attending mainstream schools and one was attending a specialist school that catered for pupils with no global learning disability.

Table 7
Parents' characteristics

Participants	Gender	Ethnic Origin	Relationship to person(s) supported	Diagnosis of person(s) supported	Age of person(s) supported	Gender of person(s) supported
P1	F	White British	Mother	Autism	11	F
P2	F	White British	Mother	AS	14	M
P3	F	White British	Mother	AS	17	M
P4	F	White British	Mother	Autism	14	M
P5	F	White British	Mother	AS	14	F
P6	F	White British	Mother	Autism	17	M
P7	F	White British	Mother	Autism	11	M
P8	F	White British	Mother	AS/AS	11 and 12	M and F
P9	F	White British	Mother	Autism and ADHD	12	M
P10	F	White British	Mother	Autism	11	F

Table 8
Young peoples' characteristics

Participants	Age	Gender	Diagnosis	Age of Diagnosis	EHC	Type of School	Additional Support Received
P11	14	M	AS	7	NO	Grammar School	None
P12	17	M	AS	7	YES	Specialist School	Speech and language group; Befriending scheme
P13	14	M	Autism	11	YES	Mainstream with a unit	Counselling at school; Youth Club
P14	14	F	AS	7	YES	Grammar School	Service A-local service offering support to vulnerable youth
P15	17	M	Autism	12	NO	Mainstream	CAMHS; Autism groups
P16	11	M	Autism	7	NO	Mainstream	Physiotherapy; Speech Therapy; Service B- Local Service organizing activities for youths
P17	11	M	AS	11	NO	Mainstream Independent	None
P18	12	F	AS	12	NO	Mainstream Independent	Private Psychologist
P19	12	M	Autism and ADHD	7	YES	Mainstream with a unit	CAMHS
P20	11	F	Autism	9	NO	Grammar School	Autism and Anxiety groups

4.4.5.4 Data collection procedure

Data collection came to an end when the researcher concluded that any new information would have a minor or no influence on themes that appeared to be emerging and it was believed that saturation was reached (Guest et al., 2006). As interviews were conducted within a short period of time, it was not possible to analyse each one of them before moving on to the next. Reflection enabled the researcher to judge whether any new interviews will contribute significantly to the overall findings.

All the young people opted for the face- to- face interviews and did not request any of the electronic options. The majority of the participants (*N*=18) were interviewed at their homes. One mother chose to have the interview at a gatekeeper's premises and another one chose a café in her town. Interviews with young people lasted on average 30 minutes and interviews with mothers lasted on average 60 minutes.

Four mothers were present in the room during the interviews with the young people. One young participant asked his mother to stay during his interview while in another three cases mothers chose to stay in the room. Although the researcher made it clear that the mother's presence was not required, the decision was left with the participants who were encouraged to choose the arrangement that would make them feel more comfortable. In a fifth case one young participant was present during the interview with the mother. The mother believed that it would be useful to consult with her daughter if in doubt regarding the details of the support she had received. Again, the researcher stressed that there is no need for the young person to stay in the room during the interview, however the final decision was left to the participants.

Three of the interviews that took place at the participants' homes were subjected to brief interruptions, when other family members entered the room and one interview was subjected to a twenty-minute break. Two of the mothers became briefly tearful during their interviews. The researcher, after reassuring them that she felt comfortable with their emotional outbreak, allowed them some time to recover and their consent was sought again before continuing with the interview.

4.4.6 Analysis

Data were analysed with Thematic Analysis following the principles of a six stages process as outlined by Braun and Clarke (2006). Analysis was facilitated by NVivo10. Interviews were transcribed verbatim, and initial codes of every meaningful quote were developed. Initial codes were then organised into potential themes, followed by the review and refinement of main themes and sub-themes. The final stage involved defining and naming the themes. All themes were produced inductively and were strongly linked to participants' accounts.

The researcher along with the primary supervisor discussed the textual data and agreement was reached between the two before finalizing the themes and sub-themes. Themes were also peer-reviewed by the whole supervisory team. Analysis began with 2 interviews of young people followed by 2 interviews of mothers. This process continued until all of the data were incorporated. The aim was to enable both groups of participants to contribute equally to the development of themes and sub-themes, rather than allowing only one group to drive and dominate the process.

In Thematic Analysis there are not any clear guidelines on deciding on what counts as a theme or what size a theme should be. This decision usually depends on the prevalence of evidence of a theme both in terms of space within each data item and across the entire data set (Braun & Clarke, 2006). It is usually expected that there will be a number of instances of the theme across the data set. However, there are no rules indicating what proportion of the data set needs to display evidence of a theme in order to be considered a theme (Braun & Clarke, 2006). Therefore, researcher judgement and flexibility are necessary to determine what a theme is.

During the analysis, prevalence across the data set played a significant role in defining a theme and a subtheme. At the same time the depth and richness of participants' accounts also played an equally important role when finalizing themes and subthemes. Well-developed narratives, reflecting unique and significant personal experiences and views, relevant to the research questions were also considered as themes even if evidence were not always prevalent in other items within the data set.

The aim of the phenomenological approach is to develop an understanding of the meaning, structure and essence of a phenomenon for a person or a group of people (Lyncoln & Cuba, 2002). In this context allowing participants to tell their own stories is crucial. Thematic Analysis is a method independent of theory and epistemology which can be applied across a range of theoretical and epistemological approaches (Braun & Clarke, 2006). This theoretical freedom is making Thematic Analysis a flexible research tool (Braun & Clarke, 2006). Therefore, it can provide rich and detailed data depending on how it is being used.

In this study all themes were produced inductively and were linked strongly to participants' accounts. In contrast, a deductive approach which would have been driven mainly by the researcher's theoretical or analytic interest in the area would have resulted in a more explicitly analyst-driven analysis.

Despite the fact that a bottom-up approach was employed, the questions used in the semi-structured interviews had already predetermined specific areas for discussion. Within these areas, participants had the freedom to focus on issues that were important to them.

Unstructured interviews, where the researcher does not try to influence the scope or depth of participants' responses would have allowed participants to use their own way of defining the issues investigated. This approach would have given maximum freedom and maximum control to the participants during the interview.

Despite the benefits of using unstructured interviews the semi-structured approach was essential in order to answer the research questions. A number of previous studies have already explored issues around support for young people with ASDs and the views of young people and their families (Cheak-Zamora et al., 2017; McCormack, 2017; Tobias, 2009). The aim of this study was to look specifically into life skills training, therefore more focused information was required and specific questions were used to obtain it.

The semi-structured nature of the interviews could have also influenced the analysis of the data. Since attention was paid on specific parts of the data, crucial to the research questions, it is possible that other critical aspects of data were ignored as they were not relevant to the research questions.

Due to time constraints, it was not possible to involve participants in the analysis and include their feedback. However, a two-page lay summary of the results was sent to all participants and to the gatekeepers. Furthermore, participants received an invitation, along with an expense cover offer, to attend one day public event where the study's findings were presented and discussed.

4.5 Results

Three overreaching themes were identified. The themes provided insights into the efforts that parents and young people make in order to prepare for adulthood and the resources they utilized in this process; their aspirations and plans for the future and the acknowledgment of the obstacles they will encounter; the challenges that young people face in mastering life skills and the effects on their daily lives; their views on the training and support around life skills they have received; their needs for training and support that they would require for a successful adulthood transition.

Table 9 presents themes and subthemes, the diversity within each theme along with participants' contributions to each theme and subtheme.

Table 9
Interviews: Themes and subthemes

	Building the foundations for a successful transition					Caught in between: negotiating two different bad parallel realities															Need for individualization of the support																	
	Participation in activities and strengths		Identifying support			Common challenges		ASD specific challenges						Sharing same aspirations with their peers but faced with obstacles							Previously accessed support					Requirement for mentoring and ASD specific support								Prioritizing the young person				
Participants	Strengths and interests	Participation in activities	Not knowing what support is available	Fragmentation of services	Not considered a priority	Dealing with puberty	Peer relationships	Daily living skills	Social-communication skills	Peer relationships Negative experiences	Peer relationships Positive experiences	Self-management	Sensory	Education/ Employment Aspirations	Independent Living Aspirations	Relationships Aspirations	Education/Employment Concerns	Independent Living Concerns	Relationships Concerns	General comments	Schools Positive experiences	External Services Positive experiences	Schools Negative experiences	External Services Negative experiences	Other sources of support	One to one/mentoring	Group Work	Online	Social skills/Friendships	Daily living skills	Career advice	Sex education	Mental health	Need for training	No need for training	Strong parental involvement	Some parental involvement	No parental involvement
P1-M			4	2				2	5	1	1	2		3	4		1	3	1		6	7	2	1			1		3	1		2	1	1				3
P2-M		3	3		1	1	1	3	1	1	1			2	2	2		1	1		3	1	1			8					1					1		
P3-M		1									2			3		3	1	2	1	3	5	5	17	1	6		1			1			1		1			
P4-M		4		1	2	1		5	2		1	4	1				2			1	2		1		1	1	1								1		1	
P5-M			2	4	3					3	1										13	3	4	2		3				3	1							
P6-M	1	1	1		2		3	11	1	1	3	5	2				1	2	3	1	1	4	3	2		7					3							
P7-M		3	3	1	3			6	9	10		3	1	1	1	2	3	1	1	1	4	3		2		8				3				1				
P8-M			5		1				1	3	1					2		2	1	2		3	6	1	3	2	4	6	7		1							2
P9-M	1			2		2		4		1	1			1	1			1	1	1	2		9	1	4				2	4								
P10-M							1	3	1	6	2	1				1		6	1	4	3	3	2			4	1		1	3					2			

Note: Numbers indicates quotes from each participant; M=Mother/YP=Young Person; P=positive experiences; N=negative experiences

Table 9 (continue)
Interviews: Themes and subthemes

	Building the foundations for a successful transition					Caught in between: negotiating two different bad parallel realities															Need for individualization of the support																	
	Participation in activities and strengths		Identifying support			Common challenges		ASD specific challenges						Sharing same aspirations with their peers but faced with obstacles							Previously accessed support					Requirement for mentoring and ASD specific support								Prioritizing the young person				
Participants	Strengths and interests	Participation in activities	Not knowing what support is available	Fragmentation of services	Not considered a priority	Dealing with puberty	Peer relationships	Daily living skills	Social-communication skills	Peer relationships Negative experiences	Peer relationships Positive experiences	Self-management	Sensory	Education/ Employment Aspirations	Independent Living Aspirations	Relationships Aspirations	Education/Employment Concerns	Independent Living Concerns	Relationships Concerns	General comments	Schools Positive experiences	External Services Positive experiences	Schools Negative experiences	External Services Negative experiences	Other sources of support	One to one/mentoring	Group Work	Online	Social skills/Friendships	Daily living skills	Career advice	Sex education	Mental health	Need for training	No need for training	Strong parental involvement	Some parental involvement	No parental involvement
P11-YP	3	2												3							8		4			3				1								
P12-YP	1													5							3	4	12	5	3		2											
P13-YP	2	3							2		2	2		7			1							3		3			2									
P14-YP	3						1		6	5	1	2	1	2			1	1			16			6					2		1							
P15-YP	1						3		1		1			5	2		3				2	1																
P16-YP	1	2									3			4							2																	
P17-YP	4								1	2	1			2							1									1	1							
P18-YP	2	2					3				1			2							2	4							2									
P19-YP	5									1				1							2	2	11		1													
P20-YP	5	1						1		1	1										1				1													

Theme 1: Building the foundations for the future.

Subtheme 1a: Focusing on strengths and interests and encouraging participation in new activities.

Although approximately half of young people were in early adolescence, they and their parents had already started thinking about adulthood and informal preparations were taking place. Parents were actively seeking to help their children to identify and further develop their skills in certain areas. Young people's interests and aptitudes were providing the foundations for future career choices, similarly to their neurotypical peers.

"(…) In terms of employment we kind of push the art thing because it is what he likes and what he is good at"

(P9-Mother of a 12-year-old male)

Furthermore, young people did not appear isolated. On the contrary they were actively engaging in a number of activities, which were available either within school or from other providers or organised by friends and family. At the same time, they could identify and experience certain benefits because of their involvement and participation.

"*More recently I have been going out with a group of people, we would just sit and play games (…) I feel like it has helped me in terms of confidence and in terms of my ability to speak to people*"

(P11-14-year-old male)

Again, mothers played a big part in motivating and encouraging their children to engage with new activities, while making use of widely available resources.

“I’ve got to let him do these things [going on school trips abroad] (…) because if you don’t let them do those things they will never learn anything about independence”

(P4-Mother of a 14-year-old male)

Mothers believed that their participation will help young people to acquire valuable life skills and will prepare them for the tasks and responsibilities they will have to undertake when they reach adulthood.

Subtheme 1b: Trying to identify available support but faced with confusion and lack of clarity.

This issue was raised only with mothers as they were those responsible for arranging support on behalf of the young people. In addition to their own efforts, mothers were also trying to bring together additional resources and enlist assistance from professionals. They described their attempts to identify and access available support and certain obstacles they faced.

Approximately half of the mothers did not know what support was available around life skills, either from schools or other services, currently or when their children will reach adulthood and how to access it. Knowledge among mothers did not seem to increase as young people reached mid and late adolescence. This finding was consistent among the mothers of young people in different age groups.

“In school I don’t think they ‘ve got too much in place for them for when they leave, but then I don’t know, I haven’t spoken to them, I don’t know what’s available this is all new for me (...)”

(P7-Mother of an 11-year-old male)

“*We just need this narrow bit of social skills from somewhere that I am still trying to find where we ‘d get that, but I don’t think it will take long to get, I don’t think it’s impossible, it’s just finding that very niche person or group or whatever it is to give that”*

(P8-Mother of an 11-year-old male and 12-year-old female)

Fragmentation of services was also creating difficulties. Different provisions were available in different locations and it was not always clear who was responsible for the care of the young person. Involvement of different services was also problematic, as in some instances they were providing contradictory advice and recommendations, creating a very difficult and often stressful situation for the families.

"*When I talk to other mums in these sort of groups they all say the same thing that's why I go to all of them- oh who are you with? who did you call?- and there are in different places- you are from (area) I am from (area) there is help for me there it isn't any here but there is help (service A) you've got it in (area) but I can't get it here because I am in (area) (…) So, there might be something out there but I don't know, I haven't had it, I haven't come across it and I am always searching for something"*

(P7-Mother of an 11-year-old male)

"*What we always used to get from CAMHS it's the autism it's the autism and then talking to the paediatrician it's mental health and we were constantly getting banded backwards and forwards between two teams*"

(P9-Mother of a 12-year-old male)

Not having access to certain types of support was also reported by a number of mothers.

"*I don't get any help because social services say he does not meet the criteria even though he has got a statement"*

(P4: Mother of a 14-year-old male)

"With external support the delays came in (…) and I think probably because she is at Grammar School people say, oh no she is not high priority"

(P5: Mother of a 14-year-old female)

Mothers believed that their children were either not considered a priority from schools or services or were not entitled to what they described as much needed support because they were high functioning.

Theme 2: Caught in between: Negotiating two parallel but different realities.

Subtheme 2a: Experiencing the common challenges of adolescence.

Although young peoples' struggles in all areas were being shaped by the deficits that characterize ASDs, some of their challenges could be described as fairly common among neurotypical adolescents. Facing the physical and psychological changes that occur during puberty, managing relationships and dealing with peer rejection and isolation are common experiences of growing up for both young people with ASDs and their neurotypical peers.

"He was quite upset a while ago, he said one minute I feel very happy mum and then I feel really sad and I don't understand. I said I think you might be starting puberty and it is all about your hormones"

(P9-Mother of a 12-year-old male)

"In the books that we are reading they were saying that when you get into teenage years all the rules go out of the window, so even if they 've learned that they don't say these things to people and they don't do this and they don't do that, none of it works when it's teenage boys trying to impress teenage girls"

(P2-Mother of a 14-year-old male)

The view that not all their challenges were directly related to their diagnosis, was strongly reflected in young peoples' accounts where they described their difficulties in trying to build and negotiate relationships with their peers.

"It's quite hard most of the time [talking about school] because I have not got a very nice year, so people aren't very nice"

(P18-12-year-old female)

All these are indications that, at least to some extent, young people with ASDs are on an equal level with their peers in some of their daily struggles.

Subtheme 2b: Facing additional challenges related to autism.

Some of the challenges experienced by young people were more common among individuals with ASDs, as they reflected marked deficits in life skills. While describing their difficulties, young people talked in detail about peer relationships and social and communication skills, whereas mothers reported a wide range of challenges including self-management and daily living skills.

Young people were struggling to master aspects of every day functioning such as handling money, maintaining their personal hygiene and appearance, keeping themselves safe and getting organised.

"She has no clue to the value of money and that side of things and that bills need to be paid and all of that"

(P1-Mother of an 11-year-old female)

"If I said to him right, you need to do your UCAS application, he wouldn't know where to start and despite having lots of paperwork about it he wouldn't know where to start"

(P6-Mother of a 17-year-old male)

Social and communication difficulties were also prominent as young people were finding it challenging to join in peer conversations, recognise emotions in others and express their own, couldn't understand humour or when they were being teased and preferred to interact with others in their own way. Making and maintaining friendships were also among their main concerns and they had often experienced teasing and bullying.

Young people also had positive experiences of peer relationships and in their majority, they could identify at least one peer who would describe as a friend. However, mothers were a bit sceptical about the quality of these relationships, although they could recognize their significance and benefits.

“It’s this understanding of people being sad or happy, it’s been a bit confusing and even if they smile I don’t understand why they smile but they are not happy, a bit confusing”

(P14-14-year-old female)

“*I never had friendships, close friends that you talk to about problems. It’s more like I have light hearted conversations, I never had friendships which are closer and deeper”*

(P14-14-year-old female)

“She has got one girl from her other school that they kind of have a relationship, but they don’t- do you know what I mean- it’s a bit an acquaintance as opposed to a friendship and that’s it. She doesn’t have friends, no one who she goes to visit, there is nobody who comes to the house”

(P10-Mother of a 11-year-old female)

Furthermore, young people were often displaying severe anxiety and anger outbursts, which were interfering with their daily activities. Mothers were also struggling to manage these challenging behaviours.

“*When we are in public he might swear and things and I say, people are listening to you (name), and he will go, oh I don’t care. He will swear, and he won’t care and everyone will start looking and it can be quite difficult because I get all stressed and everything with it, and that’s why I avoid sometimes taking him if we go to the cinema or something”*

(P4-Mother of a 14-year-old male)

"*I get really nervous like getting on the bus for example, like buying things in shops, is stuff outside school"*

(P14-14-year-old female)

Sensory problems (e.g. having difficulty with sounds, smells and big crowds, eating only certain foods), although they cannot be considered life skills challenges, were also discussed by mothers, as their impact on the daily functioning was a concern for some them.

Subtheme 2c: Young people and their parents share common aspirations with their neurotypical peers, while recognizing that achieving them is not going to be straightforward

Young people and their mothers were looking forward to continue with their education, find meaningful employment, live independently and have successful relationships. Mothers were hopeful that, when the time comes, young people could move out of the family home and they would be able to succeed in this transition as long as certain supports were in place. Help from family members or living in supported accommodation were essential in assisting young people to achieve independence.

"*I would love to be able to buy a house with a really big garden and have like a granny flat somewhere of in the grounds so she will be completely on her own (…) but she has got someone there if she needed*"

(P1-Mother of an 11-year-old female)

Mothers also believed that given the right circumstances, young people could find employment and have a relationship with a partner. Understanding from employers, colleagues and potential partners were paramount in helping young people to hold a job and form meaningful relationships.

"*Because he [son] is good talking about stuff – so I think –I mean it would have to be [talking about a future partner] somebody maybe that is on the spectrum themselves or is certainly a more mature person who can understand"*

(P2-Mother of a 14-year-old male)

"I can't see him be part of a huge team that works together. I can see him do something on his own but yeah, I know he would pick stuff up and he would ask and I think if people knew and just had a hands up about, you know, just tell him if he has done it wrong"

(P2-Mother of a 14-year-old male)

Although participants were trying hard to achieve the best possible outcomes, there was a recognition mainly among mothers that accomplishing those would be rather difficult. Mothers perceived independent living as the most challenging aspect of adulthood. It required a number of different skills coming together, including the ability of young people to look after themselves and keep themselves safe while also having to undertake the responsibilities for maintaining a household. In parallel, mothers also viewed supported accommodation or assistance from family members as a failure to achieve independence rather than necessary support that will enable young people to live at their own homes. In this case, mothers did not have a clear view on what could be considered as a successful outcome.

"It is getting her to actually click that independence means that your mummy is going to step back, is going to be there but mummy is not going to be with you and I think that is something again that is got to be worked on as well"

(P1-Mother of an 11-year-old female)

Participants identified a number of obstacles in relation to education and work. Some of the mothers worried that young people may not have a realistic view of what their chosen career path would entail, and social aspects of employment were also among their concerns.

"*Part of the worry I think might be that he knows to become an architect you do need to communicate with people it is not just working in an office on your own (…) I think that worries him, I do think that is an underlying fear"*

(P6-Mother of a 17-year-old male)

"*I think (son) lives in a very fantasy kind of world. He tends to live through his computer games, he tends to think that he would go into the army or something and just shoot people"*

(P4 -Mother of a 14- year- old male)

Regarding future relationships, the majority of the mothers expressed a fear that young people's apparent vulnerability may attract partners willing to take advantage of them. One mother highlighted the danger of young people forming inadvertently inappropriate relationships.

"That honestly, that scares me to death. I would love for her to meet a chap and somebody who will see her for who she is, but my awful fear is, because she is quite vulnerable, and she would do anything to please people, that somebody would see that and they would take advantage and that scares the Jesus out of me"

(P1-Mother of an 11-year-old female)

"*I am worried about when he is an adult 19-20 he wants a girlfriend and he meets a 12-13 year old that gives him some attention and I am so afraid, and this is my own son, afraid of him not connecting that there is huge age gap there because he seems to go for the innocent mentality*"

(P7-Mother of an 11- year-old male)

A minority of young people also expressed some worries in relation to education/work and independent living.

"I have some ideas. It will probably be quite difficult when I leave school because I mean A levels, I can pick a few things but then it is deciding what I want to do because it's quite different between creative and more logical

things and what would make me happy. I don’t want to go to work, you work quiet a long time, and I don’t want to be upset in a job and not enjoying it or anything”

(P14-14-year-old female)

“I don’t know, I think most of it is going to be challenging [process of applying to university] the application, the interview, the personal statement, the writing. I think it’s all going to be quite challenging”

(P15-17-year-old male)

Their concerns were not related to their diagnosis. They were considered part of the process of growing up and having to face new decisions and transitions.

Theme 3: Need for individualization of the support.

Subtheme 3a: Mixed acceptability and efficiency of previously accessed support.

All of the young people were receiving some form of support from their schools. The support mainly included classroom assistance with an emphasis on academic progression. Young people often received help with specific subjects and were also taught strategies that would enable them to improve their organizational skills and cope with exams and changes within the school environment (e.g. attending a homework club; having a teaching assistant in classroom; being assigned a learning mentor; receiving additional assistance with English).

Only two young people, both of them attending Grammar Schools, were receiving ongoing support around friendships, socialising and self-management. School placement seemed to be the main factor in determining whether young people would receive assistance with life skills, with some schools being more proactive than others. Age or level of need did not appear to effect participants’ satisfaction with life skills provision.

“When there are problems- you know- the school is sort of dealing with it (…) *She was having lots of problems with friendships and it all happened at once and it was trying to unpick all the little strands of what was going on and now it sort of everything calmed down (…) They are very good at picking out what needs to be done and how to achieve it”*

(P5-Mother of a 14-year-old female)

“I think they have, they may be called life skills or something, but I think there are sort of discreet sessions that are about money which I didn’t have which I think would be really helpful”

(P2-Mother of a 14-year-old male)

The most common underlying reason for dissatisfaction with the support offered from schools and other services was their failure to recognise and manage the young person’s unique needs. In relation to the support received from schools, specific examples included:

- School that did not provide any support around unstructured break time.
- School that did not share adequate information with teachers about son’s condition.
- School that could not understand son’s specific difficulties.
- Support offered in the school unit was not appropriate for the young person.

These situations were occasionally causing significant distress to the young people. Mothers noted that schools did not always communicate with them and also education providers appeared unwilling or reluctant to listen to them and take on board their recommendations. Nevertheless, they believed that schools should make use of the expertise they had acquired from caring for their own children as they had significant role to play in their child’s support.

“*A lot of the teachers I had in my previous schools were unkind to me and it wasn’t just the teachers who were teaching me it was also the senior staff at the school, lots of the schools are very intolerant, they were intolerant of me*”

(P12-17-year-old male)

“*There were a lot of things that this assessment put in place that the school should have been aware of to support him better. When I was told everyone was aware, it was on the system, all the teachers know blah blah blah I just thought they are a lot of rubbish. Parents evening not one of them knew, not one of them, in fact his form tutor said oh didn’t know he was even diagnosed as autistic”*

(P3-Mother of a 17-year-old male)

Participants also discussed some less appealing aspects of support they received form external services. A number of young people had experience of attending various groups and among their negative aspects they highlighted the mixed ability levels of the participants; feeling uncomfortable talking to people that they did not know very well; not getting along with group members.

Timing was another issue as the young person would be facing a new challenge by the time the external support would arrive. Occasionally, participant*s* found the suggestions from the professionals not workable or unhelpful due to the diversity of individual circumstances of a young person with ASD.

“There were several other speech and language therapists who would come around a club for people who had difficulties socializing with other people. I wouldn’t say that I particularly appreciated it, I did towards the end. A lot of the people there were much much less able than I was, so it meant that I didn’t really enjoy it because there was no one there really that I made friends with particularly (…) Most of the children there were very very disabled compared to me. I was the most able person and that made it quite difficult for me actually because I –to be happy in an environment- I need to have people that I get on with, I can socialize with and so although they did

provide support it wasn't something that I particularly enjoyed. I often felt that it was quiet condescending"

(P12-17-year-old male)

Participants also referred to a number of cases where they had positive experiences of support. This outcome derived from the alignment between the support and the young person's specific needs. Examples included:

- Support from CAMHS that improved the relationship between mother and daughter.
- Psychotherapy that helped son overcome his anxiety.
- Daughter who really enjoyed autism/anxiety groups because she learned about her condition and could be herself.
- Communication group at school which improved son's understanding of social etiquette and social skills.
- Support around friendships in school
- Mentor who modelled with peer- relationships with son.

"It was quite good [talking about the Communication Group] because there were not many people there just me (name) (name) and I knew both of them so it was nice with the group I kind of learned to carry on conversations talking with friends and things"

(P5-17-year-old male)

"She really, really enjoyed the groups. I think she was quite upset when she finished also because there are children like her so she can be herself she doesn't have to suppress herself"

(P10-Mother of an 11-year-old female)

"He had access to the unit, so they intervened when they needed to. I think some of his friends were maturing a bit more quickly than he was and that was a problem for a bit so that seems to have settled down"

(P2-Mother of a 14-year-old male)

Mothers would also utilise a number of other resources as part of their efforts to meet the specific needs of the young person. They had organised privately training and were using their own knowledge and expertise to support the young person. Popular culture such as books, television series, and films were also considered useful as they were helping young people to make sense of their own experiences and at the same time "normalise" their behaviour and feelings.

"*I am in an educational establishment, so I could kind of talk to people. I have a special needs coordinator, I've been on training about teaching children with autism so I had probably more of an idea than other people"*

(P2-Mother of a 14- year-old male)

"Rosie Project was brilliant, but again a man who has got no self -awareness over what he finds difficult and it's again when and how do you learn that? Then you are already so separate to integrate you don't get practice in integrating because you already set yourself so apart. So, I am not sure that it does help really, but I guess awareness is good but because it's a spectrum and is so broad it doesn't help us if we are in the high end of it because there is no distinction"

(P8-Mother of an 11- year- old male and 12 -year- old female)

Again, mothers highlighted that the usefulness of any resource depends on individual circumstances.

Subtheme 3b: Shifting the focus to the individual-The requirement for mentoring and ASD specific support.

Participants further reinstated their desire for "personalisation". This need was reflected in their accounts regarding their desired training and support. Individual characteristics, personal preferences and needs shaped participants' views and mentoring/befriending was identified, mainly by mothers, as the most desirable form of support.

Emphasis was placed on the relationship between the young person and the mentor. Mothers also highlighted the support that mentors can provide for the young people during transitions.

“So what works is befriending, and it needs to be someone slightly older and who has an understanding (…) so you need that tolerance around you, those befriending things to continue to learn the skills (…) then as you begin to catch up developmentally those skills can be transferred into normal peer friendships more easily”

(P3-Mother of a 17-year-old male)

“Well, I suppose one thing for people going from one school to another is if they have autism or they have nervous problems or things like that is who they feel they can trust, who will help them at least for the first two months and then gradually, I would say, introduce them to the other people who are similar to them”

(P11-14-year-old-male)

“*It seems to me that there isn’t much support at all as you get to those higher ages, you know starting a job, university, other than the mentoring which perhaps is something that would be really useful. Again, a bit like a school mentor for them now to talk through social skills is actually having a mentor at university which we had when we were there about 20 years ago. I am not sure, I hear that the pastoral care and the mentoring is being cut back, there is not much and actually where is your safety net there? I guess it is the mentoring but again, if they get the job depending on the job actually, there might be mentoring through that as well”*

(P8-Mother of a 11-year-old male and 12-year-old female)

“She needs somebody that has an interest to know more of her problems and her struggles (…) just somebody to talk to when she is feeling a bit off. At the moment, everything is coming home, rather than being dealt at school it’s been brought home but that don’t need to be, emotionally wise, worry wise that could be left at school to the right person. (…) If she has one

person, whether it will be an older child in sixth form, a teacher, a TA, somebody along those lines that she could confide in any little worries will make her- and I think me- a little happier, will make things a little bit easier rather than having to keep it all in until she comes home"

(P10-Mother of an 11-year-old female)

Participants also discussed two additional types of support: group work and an online platform. In relation to group work, they highlighted certain benefits (e.g. opportunities for learning and also practising life skills; training that could be easily integrated within the school as part of a club).

However, certain concerns were also expressed (e.g. the logistics of accessing such groups, difficulties of bringing a group together in a mainstream school; being viewed as a prescriptive way of teaching life skills; potential difficulties from the inclusion of participants with mixed abilities and the disadvantages of being in a group with people who you don't get along with) and participants believed that group training cannot always meet their specific needs.

"I think groups are good, groups are a good idea but is finding the time, it is all about time. At school you are not going to get a group like that, at school you are not going to"

(P10-Mother of an 11-year-old female)

Finally, videos demonstrating the use and application of specific skills, were considered as a useful and easily accessible teaching method. Again, it was emphasized that their use would only be effective within a specific context where young people would feel comfortable with the person who would be utilizing them as part of the training.

“*I only found two (videos) I think, but they seem really good so I suggested we sit down with her, hey (daughter) look what I‘ve found, but she was very reluctant because it’s me doing it, it needs to be somebody else, and if somebody else doing it I think it could be very useful for her but it needs to be somebody separate to their parents that’s a bit cool”*

(Participant 8-Mother of an 11-year-old male and 12-year-old female)

Participants identified a number of areas where they would like to receive additional support as the generic support that is available to neurotypical adolescents was not considered adequate. These areas broadly reflected the challenges that participants had identified and included:

a. Social-communication skills and friendships.
b. Career advice.
c. Daily living skills.
d. Sex education.
e. Mental health support.

“Yeah a hundred percent [help] with socializing with new people. Sometimes with other people I find it a bit hard because I don’t know what to talk about with them, mostly everything is boring, most subjects are boring to talk about with your friends and also gets a bit repetitive too”

(P13-14-year-old male)

“*I think friends is quiet a big one and stuff like that, but I think that you can get along at school and stuff with lessons and everything that’s finished, then it’s only friends which make quiet a lot of school though. I think that’s the main bit people will need help with”*

(P17-12-year-old female)

"*It's the nature of how someone like (son) who finds words difficult and saying the right words, how someone like (son) doesn't disadvantage himself in the process when he can't- you know- sell himself at the personal statement which is the thing that universities look at, that's the worrying thing"*

(P3-Mother of a 17-year-old male)

"So, it's all the little things isn't it? All the little things that everyone learns as they are growing up easily they just need that extra little extra bit"

(P10-Mother of an 11-year-old female)

Again, mothers identified various areas such as daily living skills; career advice and mental health where support would be beneficial, while young people focused on social communication skills and peer relationships.

Subtheme 3c: Prioritizing the young person.

Mothers did not describe any specific requirements for training tailored to their own needs as they believed it would be more useful if such training was provided directly to the young people.

"I think people focus so much on the parents, a lot of training and everything else but then they forget it is actually the child who needs it you know"

(Participant 10-Mother of an 11- year -old female)

"I 've been on parent training courses and to me it's (son) who needs the help not me. If (son) had help to deal with his anger- you know- things would be so much calmer at home"

(Participant 2-Mother of a 14-year-old male)

The majority of mothers did not express a strong desire to be involved in the young person's training and preferred to keep a separate role, although some were willing to work alongside providers if needed. Mothers were aware that their children will need long term, ongoing support, however they believed that young people would be more receptive if the training was delivered by someone external to the family. Mothers also expressed the view that adolescents would be reluctant to discuss and receive advice and support from their parents.

“*I know I am a teacher myself and I know if I give advice to a child that carries more weight than if mum says it”*

(Participant 2-Mother of a 14-year-old male)

“*I am quite happy for the school to do it but it is nice to have an update and know what is working and what is not working and also things that you can continue at home”*

(Participant 9-Mother of an 11-year-old male)

Additional obstacles such as being a single parent, having to care for younger children or other family members further impacted that ability of mothers to provide the levels of support that they considered desirable.

4.6 Discussion

The aim of this study was to investigate the views of young people with high functioning ASDs and their parents in relation to life skills training and support they had received and also their needs for future training. This is the first study to explore the views of these two groups regarding life skills provision in the UK and the first to directly consult with them about what kind of interventions and supports they would like to be widely available.

Although the participants identified areas where they would require additional assistance, they did not express a need for highly structured support. This can be attributed to two factors. The young people who were part of the study had not accessed structured support around life skills in a continuous and prolonged manner. Therefore, they may have not been able to perceive this as a possible option or contemplate the potential benefits.

More to that, the age range of the young participants (early to late adolescence) and their experiences from previously accessed support may also influenced what they viewed as suitable form of support. All of the young people in the study had received various types of support and assistance. Despite the challenges they faced, they were able to develop a range of life skills, were taking part in social activities and had some positive experiences of peer relationships. They were perceived to have a number of more specific and individual needs rather than developing and applying general life skills. Throughout these preparations, they were already utilising means and resources widely available. Therefore, it is possible that their requirement was for support that would be easily integrated into their daily lives and work alongside the available provisions, rather than something completely distinct and separate.

In this context, mentoring/befriending was identified as the most desirable form of support mainly by mothers. The strong requirement for individualisation of the support, could have resulted in a belief among mothers that mentoring/ befriending can best meet this expressed need. This is in line with findings from previous studies in which parents had voiced a preference for individualized support (MacCormack, 2017; Tobias, 2000). In the present study, mothers explored this approach in a more detailed manner and were able to further specify the need for individualization. Emphasis was also placed on the quality of the relationship between the young person and the mentor.

The majority of young people were not able to describe specific types of support that they would consider beneficial. However, most of them talked about difficulties with their peers and expressed a strong need for support around friendships and socialising. It is possible that the need for mentoring/befriending, as expressed by mothers, underlines young people’s need for assistance with peer relationships, although young people themselves were not in a position to articulate this clearly.

Literature further supports the potential positive impact of mentoring. According to Karcher (2005) mentoring can facilitate changes in self-esteem, self-management and social skills in neurotypical peers. In Giarelli, Ruttenberg, & Segal (2013), young adults with ASDs expressed the view that support from a peer mentor would be beneficial during adulthood transition.

The majority of life skills interventions designed for high functioning young people with ASDs provide group training (e.g. Herbrecht, et al., 2009;

Hillier et al., 2007; Lerner et al., 2011; McMahon et al., 2013; Minihan et al., 2011; Mitchell et al., 2010; Ozonoff & Miller, 1995; Palmen et al., 2008 Stichter et al., 2010 Tse et al., 2007; Webb et al., 2004; White et al., 2010). In contrast, the effectiveness and applicability of one to one training and specifically mentoring/befriending were not widely explored among this population. Only a limited number of interventions, designed for high functioning young people with ASDs, offer mentoring programs (Curtin et al., 2015; Koegel et al., 2013; Siew et al., 2015).

Mothers' preference for mentoring/befriending also echoes a need for support that can be easily implemented in a school environment. Mothers, although aware of the benefits of group work, stressed the difficulties of bringing together a group of young people with ASDs, especially in a mainstream school setting. Young people with ASDs are increasingly attending mainstream schools that may not always cater for large number of pupils with ASDs or have specialised units. Five of the young people from the study attended a mainstream school that did not have a specialist provision. This reality makes it increasingly unlikely for any type of group training to be delivered widely within mainstream schools.

Therefore, mentoring/befriending was viewed as a more viable option. Furthermore, mothers believed that mentoring/befriending could continue beyond school and support young people through various transitions (e.g. going to university/starting a job) in their lifetime. Few interventions offer evidence of long-term implementation (Hillier et al, 2007; Koegel et al., 2012;2013; Minihan et a., 2010) and even a smaller number are delivered within a school setting as part of the regular activities (Koegel et al., 2012; Laugeson et al., 2014; Minihan et al., 2011).

The majority of participants could not describe any specific, concrete and consistent form of life skills support they had received from their perspective schools. According to mothers and young people, schools focused mainly on academic skills and efforts were made to help pupils with ASDs get the most out of the mainstream classroom. At the same time, they emphasized that additional support around life skills can be equally crucial in assisting young people to achieve the best possible outcomes in life.

A somewhat surprising finding was that young people in this study were taking part in various activities offered widely either by schools or other services and organizations. This contradicts a previous study by Brewin et al., (2008) where parents expressed the view that a major barrier to social participation is that certain activities, currently available at schools such as sports, are not suitable for their children. They suggested that pupils with ASDs should be offered the opportunity to participate in activities that they have an interest in (e.g. computer games, trading cards).

Literature has consistently documented that individuals with ASDs can have obsessive (Baron-Cohen & Wheelwright, 1999), circumscribed (Turner-Brown et al., 2011) and restricted interests (Szatmari et al., 2006). The present study showed that, whether such interests were prevalent, these did not seem to be a barrier. On the contrary, young people were engaging with a variety of social activities and most importantly with those available at their schools.

Clubs and after school activities are ‘natural’ opportunities for learning and practising life skills. However, these may not be fully utilised in order to increase the benefits for pupils with ASDs. There is evidence that participation in extracurricular activities has positive associations with adolescent functioning (Darling, 2005; Feldman & Matjasko, 2005; Hansen, Larson, & Dworkin, 2003). More to that, parents have expressed the need for ongoing social skills training at schools, where their children can actually practice these skills with their peers (Brewin et al., 2008). The engagement of young people in extracurricular activities provides the basis for more structured forms of support that can take place and can also involve neurotypical peers. Research in the area of ASD interventions has showed positive results in this direction (Koegel et al., 2012).

Mothers did not express any specific needs for parental training and believed that training would be more beneficial when offered directly to young people. They also expressed their desire to allow more independence to the young person and preferred to keep separate role as mothers instead of acting as a primary support person. They also appeared willing to work alongside providers if needed. This finding revealed signs of parental conflict.

It is possible that issues around the life skills provisions, combined with lack of structured and continuous support, make it difficult for mothers to negotiate their relationship with their children and their involvement in any support arrangements. Furthermore, participants described a number of negative experiences where the received support and assistance failed to consider the specific needs of the young person. Mothers often struggled to work together with schools because they felt that their views and advice were not heard. Therefore, mothers may wish to take a step back, however they are reluctant since they feel that their continuous input and presence is necessary.

Despite these obstacles, research suggests that involvement of parents is beneficial. The potential benefits include increased skills and reduced stress for parents as well as children (McConachie & Diggle, 2007). Parents can also assist their children in practicing and applying newly learned skills. (Karst et al., 2015; Laugeson et al., 2009). This has been acknowledged and a number of interventions designed for high functioning young people with ASDs include a parent component (Dekker et al., 2015; Gantman et al., 2012; Laugeson et al., 2009, Laugeson et al., 2012; Laugeson et al., 2014; Mitcell et al., 2010; Schohl et al., 2014; White et al., 2009; Yoo et al., 2014). However, as this study showed, their involvement should not be taken for granted or considered positive as it may run contrary to their own aspirations and needs for independence.

In addition to the challenges regarding the support they had already accessed, mothers also struggled to identify life skills support that would help them, and the young people prepare for adulthood. Preparing for adulthood is a particularly difficult process, as it requires individuals with ASDs and their families to create a plan where their preferences and needs are matched with the available resources (Friedman, 2013).

However, mothers in the present study were not always aware of what support could be available either from schools or external services. Furthermore, they had limited knowledge regarding the support that young people could access when they will reach adulthood. It has been highlighted that family members of individuals with ASDs may not always be aware of the support and services that exist (Bromley, Hare, Davison, & Emerson, 2004; Nicholas et al., 2017) and the findings of this study further confirm these concerns. Communication and co-operation with schools often appear strained, placing additional obstacles in their efforts to access and fully utilize available support. It is possible that this lack of knowledge and information could potentially prevent families from making use of all the existing resources.

When it comes to adulthood, it is often expected that the parents will be primarily responsible for organizing and maintaining services and activities for their children with ASDs and continue to provide care and support throughout their life (Smith & Anderson 2014; Seltzer et al., 2003). Mothers in the present study had acknowledged this possibility, however some signs of parental conflict emerged again.

Regarding independent living, mothers were aware that young people will probably require some input. This was considered both a positive outcome, to the extent that it will allow young people to experience some independence, and a negative outcome, as this independence will be limited since they would still require support. Parents recognized that their support will help young people to achieve better outcomes in life, while at the same time considered the provision of support a declaration of failure to lead independent lives.

Young people with high functioning ASDs and their parents are living between two parallel realities. One where they share experiences, skills, abilities, interests, aspirations and challenges with their neurotypical peers, and one where they have to face their own unique and significant difficulties and obstacles. In this context, finding a balance and managing expectations appears to be rather complicated. Limited experiences of support may have made it even harder for mothers to handle the various responsibilities they had to undertake to support their children and to imagine how their future will look like.

4.7 Implications for research and practice

Findings from the present study highlighted the need to explore alternative options in the provision of life skills support. Group training, which is delivered in clinical settings, while often enlisting the assistance of parents it has dominated the literature while exploration of alternative models remains limited. What became clear from the accounts of young people and their mothers was the need for tailored, personalized support. Any support model, no matter how useful and effective it has proven to be, it cannot be expected to meet all possible needs which are not always shaped by diagnostic profiles. These needs are also defined by previous experiences, personal preferences, the way services, schools and other provisions operate in various areas and by other factors that shape the life of young people with ASDs and their families.

In relation to the design of future interventions and supports, findings from this study suggest that other, more age appropriate options, such as using peers or mentors to assist young people to learn and practice life skills could also be explored more consistently. Parents may not always perceive their involvement as desirable or beneficial. Mentoring approaches are currently a minority among the interventions designed for this population. In the UK however, various befriending and mentoring schemes are available (e.g. National Autistic Society befriending\e-befriending; Sheffield Hallam University mentoring program).

Mentoring could cover a wide spectrum of needs, from providing companionship to more focused and regular life skills support. Future design of interventions could further include the implementation and evaluation of mentoring schemes for high functioning young people with ASDs. More structured support could start at a young age and could be combined with something more flexible such as befriending/mentoring that will be more easily tailored to the specific needs of each young person.

Schools could also make better use of existing resources to provide extra opportunities for life skills training. Findings revealed that at least a proportion of young people with ASDs, are actively engaging in after school activities. A number of resources already available in schools could be better utilised to provide increased structured opportunities for developing life skills and improving peer relationships.

Furthermore, the communication and co-operation between parents and schools may be an area which requires further improvement since currently, the interaction among them often appears strained. The parents' involvement in interventions designed for their children should not be considered as a given and should be negotiated in each case.

4.8 Interviewing young people with ASDs: insights and recommendations

There is no single approach to conducting interviews with young people with ASDs. Different types of support should be in place to allow them to have their say (Harrington, Foster, Rodger, & Ashburner, 2014). Little is known about approaches that maximize participation and researchers are encouraged to share their experiences to contribute to a better understanding (Beresford, Tozer, Rabiee, & Sloper, 2004; Harrington et al., 2014). This section will present insights from interviewing 10 young people which could shed more light in the process of engaging individuals with ASDs in qualitative studies.

Autism is a spectrum and therefore, all individuals with ASDs share the core symptoms. However, their experiences can vary significantly as these symptoms can have very different manifestations and their potential impact should be considered when conducting research studies (Preece, 2002).

Previous studies had identified the various ways in which these characteristics can impact on the research process (Beresford et al., 2004; Preece, 2002; Preece & Jordan, 2010). The most relevant characteristics for this research were social anxiety; poor memory; staying on topic; difficulties discussing preferences, difficulties expressing emotions and concrete thinking. Young people who took part in the study did not have an intellectual disability and they were all able to communicate verbally. Alternative means of communication such as craft making activities; photographs etc. were not necessary to enable them to describe their experiences and share their views.

Social anxiety

One of the main goals of this study was to make the interview an enjoyable experience for the young people. Parents encouraged and supported young people into taking part, believing that this will be a positive and valuable experience. Some parents also viewed this as an opportunity for life skills training, since young people could engage in a conversation and share their thoughts and experiences with another person.

The majority of the young people, six out of ten, appeared anxious at the beginning of the interview with the females exhibiting more signs of anxiety (e.g. avoiding eye contact; slightly trembling voice; shorter answers) than males. However, it was possible to overcome this initial anxiety as the interview progressed. During the first part of the interview, the researcher engaged in a discussion with the young people about their interests and activities, giving them the opportunity to talk about something they felt comfortable with.

Furthermore, the questions were open and were not creating the impression that there were right or wrong answers. On the contrary, they were encouraging young people to share their experiences rather than looking for the answers that could please the researcher. Direct questions about difficulties were avoided so as not to upset the young people. The focus of the discussion was their daily lives and their future aspirations. Within this context, difficulties were identified and further explored. Actively listening to young people and trying to understand their experiences were key in making the interviews meaningful and enjoyable for them. At the end of our interview, a 14-year-old male said "*thank you for understanding*", something that shows that the act of listening and trying to understand the experiences of the individuals involved in the research situation can have a powerful impact. It can also provide meaningful data, even with participants who may struggle with some of the aspects of qualitative investigation.

It is often recommended spending time with the young people prior to the interviews and engaging in shared activities in order to create a rapport (Harrington et al., 2014; Preece & Jordan, 2010). Although this is a useful strategy and could even be necessary in some cases, it also places significantly more logistical demands on the families (e.g. arranging more meetings with the researcher). As a result, it increases the time they have to allocate to the research project and may actually discourage them from participating.

Spending prior time with young people also highly depends on the types of gatekeepers involved in each study. Gatekeepers such as schools or other services and organizations, where young people can spend part of their day, can actually provide opportunities for the researcher to become familiar with the young people by joining in during activities. Gatekeepers recruited for this study offered services and advice mainly to parents and limited activities for the young people.

As a result, it was not possible to acquire prior contact with the young people through the gatekeepers. In the initial communication with the families, the researcher offered to spend some 10-15 minutes prior to the interview having an informal chat with the young person or engaging in an activity. However, none of the parents thought that to be necessary. The Information Letter and Assent Form also included a photograph of the researcher to help young people familiarize with her before the actual interview.

Remembering past events

It has been highlighted that individuals with ASDs have poor memory of past events and previous experiences (Bowler, Gardiner, & Grice, 2000). This was a particular concern for this study because young people were expected, when this was relevant, to recall and describe their experiences of previously accessed life skills support. These concerns turned out to be unfounded as overall young people were able to recall and describe the types of support they had accessed, and they understood why they were receiving the support.

Furthermore, in cases where schools offered support, young people were the main source of information as mothers were not always aware of all the details. However, parental input was necessary in some occasions to identify the specific type of support (e.g. youth group, sessions with the clinical psychologist). Young people would describe the context and what was taking place but not name the support. However, this could be attributed to the fact that the parents or the schools had arranged the support, therefore young people may not had a good understanding of the specific details.

In all cases, young peoples' accounts were triangulated with those of the mothers, so it was possible to acquire all the necessary information.

Staying on topic

Individuals with ASDs are often described as having very narrow, obsessive and restrictive interests (Baron-Cohen & Wheelwright, 1999; Turner-Brown et al., 2011; Szatmari et al., 2006) and their potential insistence on talking about these could derail the conversation. However, young people in this study had no difficulty in focusing and engaging with the questions and staying on topic.

Although two of the parents mentioned that young people were interested in very specific topics, these did not monopolize our discussion. One of these two young people, a 12-year-old male had a particular interest in drawing and talked about this during our interview in an appropriate manner. After the end of the interview, he showed me some of his drawings.

Difficulties discussing preferences and expressing emotions

Studies have shown that children with ASDs struggle to explain any character's internal states and would more often label emotions than use them in order to evaluate situations or attribute any personal meanings (Capps & Thurbar,1999). These difficulties could affect their capacity for insight and their ability to express their preferences. They are more likely to identify preferences in relation to concrete topics (Preece, 2002). Most of the young people who took part in the study were able to express their likes and dislikes in relation to support they had received.

However, they needed a lot of prompting because they tended to focus on describing the details such as where the support was taking place or its frequency, without expressing their opinions, views and feelings about the support. This was finally achieved by insistence and prompting on behalf of the researcher. Two of the young people talked specifically about their difficulties around social skills and friendships because of their ASD diagnosis. One young person appeared concerned about the impact of his aggressive behaviour, showing an understanding of the consequences of his behaviour and willingness for change.

Concrete thinking

A tendency for concrete thinking (Hill, Berthoz, & Frith, 2004) in addition to the lack of insight that often characterize individuals with ASDs could render questions about aspirations, meaningless and even threatening (Beresford et al., 2004). Additionally, the semi-structured nature of the interviews could potentially make it very hard for the young people to engage. Young people did struggle on occasions with open ended questions and it was necessary for the researcher to break them into smaller and more concrete parts.

However, the format of the interview was not considered inappropriate for the young people, but it rather required preparedness on the part of the researcher to adjust the question guide. The ability of the young people to talk about their future dependent on their age, with those in mid to late adolescence expressing more concrete plans in comparison to those in early adolescence. The researcher focused more on here and now with younger participants, whilst discussions about future aspirations were possible with older participants.

Overall, young people responded quite well to questions about aspirations although some difficulties were also obvious. A 17-year male expressed some vague anxieties about the future but could not specify them. Attempts from the researcher to bring up examples such as moving away from home and attending university, did not yield any results as the young person did not appear concerned about any of these transitional aspects. The below extract from a dialog between the researcher and the participant is an example that illustrates the difficulties in identifying more specific concerns:

"*I: (name) from what your mum has been telling me you are planning to go to University and you are preparing your applications. How is that going?*
P: Umm Ok I think it is a bit scary
I: It is a bit scary?
P: Yeah, yeah
I: Do you find the process of finding the right course and applying scary or the next step?

P: It's the fact that I am going to university or hopefully I will be going to university
I: It's a big step, it's a huge step actually, so what are the things that worry you?
P: I don't know just everything really, it's all quite scary
I: Do you have any idea about possible universities or you are still looking?
P: Umm we are looking but we‘ve got a couple, I can't remember the names
I: Are they close to home?
P: A couple of them are close in (area) one of them is in (area), it's a bit far away but I will have to get a house, rent a shared apartment thing with other people so…
I: Is this one of the things that worry you?
P: Not really, I couldn't say that worries me"

Young people responded well to the interviews. Involving young people with ASDs in qualitative studies does not only present distinct challenges but also shares the same positive aspects and advantages with any other piece of qualitative work. Furthermore, it is not always required to make lengthy and demanding preparations which can involve either multiple meetings with the family or access to various other professionals, who know and support the young people.

The study showed that although some challenges are present even with high functioning individuals, these can be dealt with within the process of the interviews, turning them into a meaningful experience, both for the researcher and the young person alike.

4.9 Strengths and limitations

The study shed light on the provision of life skills support for high functioning young people with ASDs in the UK, which is an under investigated area. Furthermore, the bottom up approach allowed young people and their parents to express their views and needs regarding their desired training and support. Young people with ASDs are a vulnerable and as such, underrepresented population in research studies and their voices are not being heard very often.

The study also had a number of additional limitations. Young people who participated were those who were able and willing to be interviewed. Therefore, those who were not feeling comfortable with the interview process would have been excluded. Furthermore, the composition of the sample was 100% White British. Future studies could include a more diverse sample to examine the potential influence of sociocultural differences. All participants were recruited from gatekeepers based in Kent, resulting in findings reflecting the experiences of services and support from a specific geographical area.

The study included young people up to the age of 17 years and not up to 21 years which was the initial aim. The wide age range of young people provided an insight into the participants' experiences and needs from early to late adolescence. However, it also created a number of complications. It was not feasible to ask parallel questions to young people and parents. Although the semi-structured nature of the interviews allowed the researcher to modify and adjust the topic guides, it was not possible to fully overcome this limitation. Efforts were made to ensure that all voices were represented equally in the study, while recognizing the difficulties that occur when trying to integrate the views of different age groups.

Another limitation was the influence of mothers on young people's expressed views and vice versa. It is believed that the presence of parents during an interview can either stop or help children's views being heard (Hellen Gardner & Duncan Randall, 2012). For some children, the opportunity to express their views without their parents being present leads to richer provision of data. However, parents can also act as proxies for researchers as the understanding of their own children can lead to the collection of rich data (Hellen Gardner & Duncan Randall, 2012).

The presence of mothers during the interviews with young people was overall discreet and, in occasions, they also provided prompts that helped young people to recall and reflect on some of their experiences of support. At the same time, it could be possible that mothers affected the narratives of young people by implicitly encouraging them to share views that they knew their mothers would approve.

The presence of one young person during the interview with the mother affected the content of the interview. The researcher was not able to ask questions regarding concerns about the future and approach the issue of personal relationships so as not to upset the young person. However, the mother may had felt more confident reflecting on the support they had received, as her daughter would had corrected any perceived inaccuracies in her narrative. Finally, the sample size was small and findings should be interpreted with caution.

4.10 Conclusion

Findings revealed potential issues with the provision of life skills support in the UK. Furthermore, they provided new insights regarding the types of support that young people with ASDs and their mothers consider desirable. The findings could help schools and services improve the support and training that is currently available and inform the design of future interventions.

4.11 Rationale for next chapter

Participants expressed the need for life skills support that would be delivered in schools, however they described mixed experiences of the support they have received from their perspective schools. They were able to express their views regarding the types of support they would consider useful and what they would like to be included in them. The next phase of the research project was to investigate life skills training and support offered in schools that cater for pupils with ASDs without intellectual disability.

Specifically, what training is currently available to these pupils, what are the obstacles that education providers encounter at their work and what improvements they would like to see at the current provisions. Findings from the next phase could provide more insight as to how closely schools meet the needs of parents and young people and what space there is for improvement in the current provisions.

Chapter 5 : Focus Groups

5.1 Chapter summary

Background: Participants in Chapter 4 expressed the need for individualized life skills support that would be available within schools and also believed that mentoring/befriending could better meet this requirement. They identified various areas that this support should target (communication and social skills; daily living skills; self-management; career advice; sexual relationships) with young people focusing specifically on peer relationships. The next step was to gain a better understanding of life skills provision in schools. This was a qualitative study with the aim to investigate: **a)** the types of life skills training and support that are being provided by the schools to pupils with ASDs; **b)** views of education providers regarding the current provisions; **c)** recommendations for future improvements.

Method: Data were collected through five focus groups that included teachers, teaching assistants and other professionals from mainstream and specialist schools. The focus groups included in total 22 participants. Data were analysed with Thematic Analysis.

Results: Education providers exerted great efforts to meet the specific needs of their pupils and tried to incorporate life skills training into daily activities. As a result of this approach however, the support was eventually applied in an informal, impromptu way, possibly limiting the use of more structured and more effective programs. The involvement of parents and neurotypical peers in the support appears to be problematic, placing restrictions in the generalization of skills and behaviours.

Conclusions: Findings revealed that although there is expertise among education providers, more efforts should be made to encourage the application of more structured and evidence-based programs, while maintaining an individualized approach.

5.2 Introduction

According to a recent publication by the NAS, fewer than 5 in 10 teachers are confident about supporting pupils with ASDs (NAS, 2017). This finding is in line with previous studies. According to Jones (2006), staff in both mainstream and specialist schools in the UK find it difficult to understand and teach pupils with SEN needs, including those with ASDs.

A study by Gregor and Campbell (2001) showed that only around 50% of experienced teachers in UK mainstream and specialist schools reported that they had specific training in ASDs. Teacher training can significantly affect overall school experience of pupils with ASDs, as it is associated with reduced social problems and an increased sense of belonging (Osborne & Reed, 2011).

It has been suggested by Leach and Duffy (2009) that teachers, particularly in mainstream schools, where most pupils with ASDs in the UK attend (DfE,2014$_a$), may not always be familiar with specific approaches that are required to teach these pupils. In a UK based study by Lindsay, Proulx, Thomson, and Scott (2013), most teachers in mainstream schools felt that they lacked training and continuing education opportunities on how to work with pupils with ASDs.

Similar findings were also reported in two US based studies. According to Robertson, Chamberlain, and Kasari (2003) and Able, Sreckovic, Schultz, Garwood, and Sherman (2015), teachers in general education classrooms were struggling to manage the behaviour of their pupils and they expressed the need for more knowledge about ASDs and individualization strategies. However, these findings are not conclusive as Humphrey and Symes (2013) reported that, on average, teachers who took part in their study felt that they were able to cope with behaviours associated with ASDs.

The social support for pupils with ASDs in mainstream schools has received adequate attention in the literature. According to Jordan (2005), these pupils need more support around free time and social periods than academic work. However, teachers in a US based study (Able et al., 2015) admitted they struggle to implement social supports for their pupils. They were uncertain on how the teaching of social skills should be incorporated into the mainstream classroom in addition to the academic material.

Although challenges do exist, Jordan (2005) has argued that social support may require effective ways of mobilizing support from peers instead of additional resources. Currently, there is an overemphasis on adopting adult-mediated support in the form of a teaching assistant at the expense of peer-mediated support (Davis, Florian, & Ainscow, 2004). However, teaching assistants might not be provided with training or with a role in enabling the pupils to have positive contact with their peers. As a result, they can actually keep them isolated within the school (Jordan, 2008). Although the involvement of peers is highly encouraged either as part of a behaviour management program (e.g. peer-monitoring) or peer-oriented intervention (e.g. buddy system) (Davis et al., 2004), it appears to be more problematic in practice.

According to teachers, peers do not show tolerance or understanding when it comes to the needs of pupils with ASDs. As a result, they are reluctant to engage them in the support (Able et al., 2015; Glasham, Mackay, & Grieve, 2004). They also stressed time constraints and limited skills in facilitating these supports (Able et al., 2015). Teachers’ individual efforts, although necessary may not be sufficient to guarantee the involvement of peers, as this process requires the existence of a strong supportive culture within the school (Emam & Farrell, 2009).

The involvement of parents, in addition to the peers’ one is also considered an essential element of any effective intervention (Jones, 2006). It is recommended that schools should maintain an open line of communication with the parents, as they know their child/ren better than schools do and could also encourage them to keep their child/ren involved in the community (Dahle, 2003). However, the relationships with parents are not without challenges. Teachers have reported that parents and families require high levels of emotional support and, there are also occasional conflicts between parents’ expectations and the levels of support that schools realistically can offer (Glasham et al., 2004).

As pupils move through the educational system, life skills support can also include more specific elements related to adulthood transition. Encouraging pupils to have high aspirations and supporting them to aim high

(Hatfield, Falkmer, Falkmer & Ciccarelli, 2017) has been recognized as paramount to a successful outcome.

Other recommendations for preparing pupils for the life after school include real-life experiences such as volunteering, work experience, part-time work and after-school community activities (Carter, Harvey, Taylor & Gotham, 2013; Hatfield et al., 2017). Particularly important for young people with high functioning ASDs may be the early acquirement of vocational experiences through after-school and summertime jobs, internships, or school-sponsored work experiences (Hatfield et al., 2017).

5.3 Research Aims

A limited number of qualitative studies have investigated the views and experiences of education providers on supporting their pupils with high functioning ASDs (Able et al., 2015; Emam & Farrell, 2009; Glasham et al., 2004). All the above studies explored several issues that have mainly resulted from the inclusion of pupils with ASDs in mainstream schools. The researcher is not aware of any studies investigating the views and experiences of education providers that support pupils with high functioning ASDs in specialist schools. Furthermore, none of the above studies have focused specifically on life skills training as they also grouped together aspects of integration in the mainstream environment and teaching of academic subjects.

One qualitative study (Able et al., 2015) looked specifically into social support in inclusive settings for pupils with ASDs however, it had a limited scope and it was conducted in the US. A second study conducted in Australia by Hatfleld et al., (2017) placed emphasis primarily on the transition planning and did not focus on school support. The present qualitative study explored the provision of life skills training and support for high functioning pupils with ASDs in UK schools who cater for this population.

The study aimed to investigate:

a. The types of life skills training and support that are being provided by the schools to high functioning pupils with ASDs.

b. Views of teachers and other members of staff who work in a learning support or educational capacity regarding the current provisions.
c. Recommendations for future improvements.

5.4 Method

5.4.1 Sampling method and inclusion criteria

A purposive sampling method was used to recruit a sample that shared common characteristics and would provide greater insights into the research questions (Devers & Frankel, 2000). There were two phases in the recruitment process. The first one was the identification and recruitment of schools. The second phase was the recruitment of participants within each school. To be included in the study, schools and participants had to meet certain inclusion criteria:

Schools

Schools had to meet at least one of the bellow inclusion criteria:

1. Special Education Needs schools that cater for high functioning pupils with ASDs aged 11 years old and above.
2. Mainstream secondary schools with autism hubs attached.
3. Grammar schools with SEN inclusion policy & adequate provision.
4. Additional Resource Units that cater for high functioning pupils with ASDs aged 11 years old and above.
5. Further Education Colleges that cater for high functioning pupils with ASDs.
6. Boarding schools that cater for high functioning pupils with ASDs aged 11 years old and above.

These inclusion criteria refer to the same types of schools as those specified in chapter 4 (secondary educational settings that also cater for pupils with no global learning disability).

Education Providers

Education providers had to meet all of the bellow inclusion criteria:

1. Teachers or other staff members who work in a learning support or educational capacity.
2. Have at least one-year experience of working with high functioning pupils with ASDs aged 11 years old and above.

5.4.2 Recruitment

Ethical Approval for the study was obtained from the Medway School of Pharmacy Research Ethics Committee (Appendix C_1). A list of schools, based in London and Kent, was created as they appeared to meet the inclusion criteria. The areas were chosen based on their geographical proximity to the University. The researcher visited the council website of every borough within London and Kent and identified relevant schools. The list included 71 schools. Most of them (45) were in London and the remaining ones (26) were in Kent.

The researcher e-mailed an Invitation Letter (Appendix C_2) to each school. If there was no reply from the school within a week, the e-mail was followed by a phone call. During the phone call, the researcher requested the contact details of a senior member of staff who was in a position to discuss the study. If these were provided, the researcher e-mailed the Invitation Letter directly to the senior staff members or had a discussion with them over the phone. If these were not provided, the researcher emailed the Invitation Letter to the school e-mail address for a second time.

When a school expressed an interest to participate, they were asked to confirm in writing that they meet the study inclusion criteria. Upon this confirmation, they were provided with a Gatekeeper Information Letter (Appendix C_3), a Gatekeeper Consent Form (Appendix C_4), a Participant Information Letter (Appendix C_5) and a Participant Consent Form (Appendix C_6). The researcher liaised with the member of staff who replied to the request. The same member of staff was also responsible for recruiting the participants, distributing Information Letters and Consent Forms to them and arranging the date of the focus group. Focus groups took place in schools as this was considered the most convenient option for their staff. The researcher collected the consent forms on the day of the focus group.

5.4.3 Ethical considerations

Ethical issues, particularly relevant to qualitative research, were considered with guidance from Houghton et al. (2010). These included maintaining confidentiality and avoidance of harm. There are additional ethical considerations when conducting focus group research such as maintaining confidentiality within group members and not pressuring participants to speak (Gibbs, 1997).

Avoidance of harm

During the focus groups, participants were asked to discuss their experiences of working with pupils with ASDs. The nature of the subject may had given rise to feelings of distress among participants. This acknowledgement resulted in the inclusion of relevant statements in the Information Letter to warn participants of possible adverse effects. It was also made clear to the participants that all their responses would be anonymous, and that the participation was voluntary. Even if they decided to take part, they would still be free to withdraw from the study any time before and/or during the focus group without having to give any reasons for their decision. Participants were also advised to visit the website of the NAS where they would find guidance and information on services they can access.

Confidentiality

From the onset of the study, it was made clear to the participants that the focus groups would be audio recorded and that any identifiable personal information would be stored securely. Audio recordings were erased after they had been transcribed and analysed. Transcripts were fully anonymized, and names of schools were removed. There are additional considerations when handling sensitive material and confidentiality in focus group research because the groups include more than one participant (Gibbs 1997). In the Consent Form participants were asked to agree on maintaining confidentiality of focus group members. Participants were also encouraged before the start of the focus group to treat what they would hear as confidential.

Not pressuring participants to speak

The Information Letter clearly outlined to the participants that participation was voluntary. However, participants may had been asked by a senior member of staff to participate. It was not possible to establish if they were under any implicit or explicit pressure to attend the focus group. Therefore, it was important not to impose any additional strains on them. While offering all the participants opportunities to express their views, they were also given the option to remain silent if they wished.

5.4.4 Reflexivity

I had no first-hand experience of life skills provision within schools. However, I had documented the views and experiences of parents and young people and as a result, I expected to encounter a rather unsatisfactory state of life skills support. Furthermore, I held the view that that education providers would try to promote and defend their work. Therefore, would be willing to discuss mainly the positive aspects, while omitting any controversial issues. Being aware of my own perceptions, I tried not to let them influence the focus group. My aim was to listen to my participants with an open mind, resist the need to challenge them instead of exploring their views, and keep the discussion free, as much as possible, of my own biases.

After each focus group, notes were taken which included my thoughts on what I believed had gone well and what could had gone better, obstacles that I encountered, any other thoughts or feelings that were occurring to me, comments that participants made before and after the focus groups. The average period between the focus groups was 3 months. This helped to transcribe each focus group and conduct a preliminary analysis before the next one. As a result, I acquired a better understanding of the various themes that seemed to be emerging and I was able to further explore them in subsequent focus groups.

Extract from the reflective diary.

The school responded promptly to my request and the focus group took place after the end of the school day, reducing the time restrictions. Before the start of the focus group, participants explained that they had started to provide a more structured training around life skills about one year ago, so they were very keen to establish contact with anyone who had some expertise in the area. I was really impressed and felt that they had a genuine interest in the study. Life skills training was something that they felt passionate about and they became aware of the need to support their pupils with ASDs through their own experiences as teachers. School was supportive, and they were given the freedom to run the training under the condition that they had to design and plan everything in their own free time. What I strongly received during the focus group was these people were working in isolation. They did not seem to be aware of resources, services, or professionals they could consult with. They appeared willing to discuss a variety of issues including some of the difficulties they face, something that made me more optimistic about the next focus groups. The discussion was interrupted a few times. One of the participants brought her 6 months old baby at the focus group and had to leave the room in multiple occasions every time the baby started to cry. A second participant left for about ten minutes to check on the homework club. However, these interruptions did not affect the flow of the discussion.

5.4.5 Data Collection

5.4.5.1 Focus groups

Data were collected through semi-structured focus groups. It is recommended that group discussions should be conducted several times with similar types of participants, so the researcher can identify trends and patterns (Krueger & Casey, 2000). Although there are no strict rules on defining sample size in focus group research, still there are some suggested guidelines. According to Stewart and Shamdasani (2014) one focus group would be sufficient while Krueger and Casey (2000) argue that the minimum may be 3 and the maximum 12. For this study, the maximum number of focus groups was set to 8, after taking time and resources constraints into consideration.

Based on the literature, the suggested number of participants in each group can vary from 3-4 to a maximum of 10 (Nyumba, Wilson, Derrick & Mukherjee, 2018). For this study, the minimum number of participants in each focus group was set to 3. There were two main reasons behind this decision. The recruitment of experienced staff, who had the task of supporting pupils with life skills, was crucial in order to meet the research aims. It was expected that a small number of staff members in mainstream schools would be working closely with this population and, therefore, they would meet the inclusion criteria. More to that, the minimum number of participants required from each school was lowered to 3 in order not to discourage schools from participating, while also efforts were made to encourage and increase participation.

5.4.5.2 Materials

The topic guide was developed with guidance from Morgan and Krueger (1998). The questions were designed with the aim to encourage conversation and to be as clear as possible. The focus groups were semi-structured. They had a limited number of set questions allowing sufficient time to participants to respond and to also exchange ideas with each other. The first focus group was treated as a pilot, aiming in validating and enhancing the clarity of the topic guide. No refinements were necessary as the questions worked quite well with the participants, raising no reasons to exclude the first focus group from the analysis.

Topic guide Focus Groups

- What are the most significant life skills challenges experienced by your pupils?
- What are the main obstacles that pupils face when they transition from school to: university/college; vocational training; employment independent living
- What types of life skills training and support are currently available to your pupils?
- How is the training and support delivered?
- What changes/improvements would like to see in the current system?
- What additional support do you require?

5.4.5.3 Participants

Most of the schools (66) made no contact with the researcher after they received the Invitation Letter. They also made no further contact after a phone call was made and the Invitation Letter was e-mailed to them again. Two specialist schools replied to the Invitation Letter saying that they do not meet the study inclusion criteria as they did not cater for pupils with ASDs without intellectual disability.

Eight schools (2 specialist and 6 mainstream) responded to the Invitation Letter expressing an interest to participate in the study. The researcher e-mailed the full study documentation to all of them. After receiving the documents, three schools made no further contact with the researcher. The researcher tried to re-establish communication with the member of staff who had responded positively to the request through phone calls and e-mails. However, no further replies were received. The final sample included 5 schools, 3 mainstream and 2 specialist, and a total of 22 participants. Table

10 provides information about each school and Table 11 describes participants' characteristics.

Table 10

Information on schools

FG 1: Community special school: 6 participants	Places are offered to learners in the ages 11-19 years, who have complex needs along with an EHC plan. Their specialism is ASDs. The school also offers a post-sixteen provision based in a local college.
FG 2: Community Mainstream (Grammar) School with an ASD resourced provision: 3 participants	Support is offered to pupils in the ages 11-18 years with EHC plan or diagnosis of ASD and it is also open to those pupils who have similar needs even if they don't have a diagnosis or an EHC plan.
FG 3: Community mainstream school with an ASD unit: 2 participants	The unit accepts pupils in the ages 11-19 years with a diagnosis of ASD and an EHC plan.
FG 4: Community special school: 7 participants	Places are offered to pupils aged 4-16 years with a diagnosis of ASD along with an EHC plan.
FG 5: Community mainstream school with an ASD unit: 4 participants	The unit accepts pupils in the ages 11-16 years with a diagnosis of ASD and an EHC plan. Access to the unit is also offered to pupils who have similar needs or experience various emotional and social difficulties, although they may not have a diagnosis or an EHC plan.

Table 11

Education providers' characteristics

Gender and Role	Number of participants
Male	7
Female	15
Teacher	13
TA (Teaching Assistant)	4
Assistant Head Teacher	3
SENCO (Special Education Needs Co-ordinator)	1
Speech and Language Therapist	1

5.4.5.4 Data collection procedure

Focus groups lasted on average 50 minutes. The duration of each focus group was determined by staff availability and other constraints within each school. Focus groups were audio recorded with participants' consent. Time limitations brought the recruitment to an end. The slow pace of recruitment and the long waiting times, (two months on average), that were required to set up the focus group with the participating schools meant that it was not possible to continue after the recruitment of the fifth school. Time considerations indicated the conclusion of data collection phase therefore, it cannot be assumed that saturation point was reached.

5.4.6 Analysis

Data were analysed with Thematic Analysis following the principles of a six stages process as outlined by Braun and Clarke (2006). Analysis was facilitated by NVivo 10. Focus Groups were transcribed verbatim, and initial codes of every meaningful quote were developed. Initial codes were then organised into potential themes, followed by the review and refinement of main themes and sub-themes. The final stage included the definition and the naming of the themes.

All themes were produced inductively and were linked strongly to participants' accounts. The researcher along with the primary supervisor discussed the textual data and an agreement was reached before the finalization of the themes and sub-themes. Themes were also peer-reviewed by the whole supervisory team. Due to time constraints, it was not possible to involve participants in the analysis and include their feedback. However, a two-page lay summary of the results was sent to all participating schools.

5.5 Results

Four main themes were identified with each one of them containing several subthemes. Themes provided insights into the life skills that the education providers have to support their pupils with; their perceptions of their pupils' difficulties; the delivery of life skills support within different types of schools; the collaboration and dynamics between education providers and parents, issues in facilitating interaction with neurotypical peers; participants' suggestions for improvements. Table 12 presents the themes and subthemes, the diversity within each theme along with participants' contributions.

Table 12

Focus Groups: Themes and subthemes

	Preparing pupils for life: Dealing with the interplay between individual and external challenges						Schools offer life skills support in an individualized and casual manner							Enablers and obstacles in the generalization of life skills						Successful outcomes require a more holistic approach to life skills training and support				
	ASD related difficulties as barriers to successful outcomes						Understanding the specific needs of the pupils and forming strong relationships are the cornerstones of a successful approach			Teaching life skills through participation in everyday activities and informal sessions				Encouraging participation in social opportunities but failing to actively facilitate interaction with peers			Maintaining an open line of communication with parents but struggling to build effective partnerships			Allocating more resources to schools while also acknowledging the limitations of the support that they can offer			Creating an environment that can foster communication, exchange of ideas and understanding	
FG	Daily living skills	Peer relationships	Self-management	Social skills	ASD challenges effecting progression	Barriers are the result of inappropriate responses to the needs of young people with ASDs	Develop own resources	Enlist assistance from professionals	Apply skills and expertise	Training part of the curriculum	Group work	Taking part in activities	Links with the community	Identifying social opportunities	Recognizing the school environment can be overwhelming	Pupils spent free time in the unit	Seeking their input in the training	Experiencing conflict	Providing practical/emotional support	Support for staff	Need for residential unit	Long term support	Improving communication between stakeholders	Advancing understanding among society
FG 1						5	3	1		3		1	3					11	1		1	6		5
FG 2	6	2					7	4	3		12			6			1			5			4	
FG 3	7			7				2	1	5		13		4	3	1	2		8	4				
FG 4	2			1		8	3	3		7		6	7					6	14			8	3	2
FG 5		1	4	2				3	1	1			12	10	1	3	1	5	7	5	3		2	1

Note: Numbers indicate quotes from participants in each FG

Theme 1: Preparing pupils with ASDs for life: dealing with the interplay between internal and external challenges.

Subtheme 1a: ASD related difficulties as barriers to successful outcomes.

While describing the challenges experienced by their pupils, education providers from mainstream schools focused on ASD related difficulties. According to their views, deficits in life skills as experienced by their pupils were interfering with their daily functioning. Among the life skills that their pupils were struggling to master, they flagged as the most significant ones social and communication skills; managing their emotions; ability to form and maintain peer-relationships; naivety; ability to keep themselves safe and various other daily living skills (e.g. taking the bus/train).

"Quite often, students once they have done something once, they have done it, so I ordered a coffee, ok I ordered a coffee three years ago with my nan in a quiet coffee shop. I didn't go into busy (name) town, I didn't do it myself (…). There are very few students I think who regularly travel by bus or travel by train but they all think, I've done the train once so therefore every train experience will be the same"

(SENCO F-mainstream school)

"Also, the aspect of interacting with each other, I mean the social aspect. We see that we need to be constantly coaching them- you know- trying to guide how to-you know- sometimes respond to- you know- small talk sometimes or sometimes could be anger and they don't know how to deal with these, they are abrupt"

(TA F-mainstream school)

Participants also touched upon the impact of external factors in relation to aspects of adulthood transition and more specifically transition into higher education. However, their focus was again on their pupils and the difficulties that they will have adjusting to a different environment and copying with increased demands.

“Where to start it is all of it though, isn’t it? It’ s almost not knowing what the expectations are. I guess if we are looking at the moving on to the academic sort of thing then they probably know that if they have done their A Levels, done the courses that they need, then know what university courses are going to have, x y z, because that’s what UCAS form says, but what to expect from university life, what to expect from freshers week, what to expect from how to get to their lectures and all the stuff that comes with it, I don’t see that they really fully grasp that”

(Teacher M-mainstream school)

In this context, outcomes in adulthood and particularly, progression into post-secondary education were mainly defined by each pupil’s personal abilities, characteristics or circumstances. Education providers believed that the support they could offer in this direction had certain limits. Some of their pupils would not be able to continue with their current placement or progress into post-secondary education, regardless of the support they would receive from school.

“A lot of the children go to college, things like that, but that’s’ what they tend to do, they go to college or they go to sixth form and then a couple went off to university last year so everything is achievable, it’s whether they can do it or not, is much like any other child really. I would imagine it would probably be that little bit more anxiety for them”

(Form Tutor F-mainstream school)

“I would like to say the support they get here, they all get quite equal levels of support. If they need more support they generally get it, we never say we can’t give that person any more support even if they are struggling, up to a point. I think there are students who have left basically because we ‘ve given them as much support as we possibly can and parents have decided that is still not working and we have agreed”

(Assistant Head Teacher M-mainstream school)

"I think it has probably to do their ability, their resilience, and their coping skills, and family support and sort of family culture as well. I would say other type of factors but I don't think they are ever really in school factors, I would never say they didn't succeed because of an in school factor, no I can't think of a student where that has been the case"

(Teacher M-mainstream school)

Education providers expressed the view that their schools offer high level of support, however this was not always enough to assist their pupils in making further progress. Other equally important factors came into play and the input that the school could have on those was minimal.

Subtheme 1b: Barriers are the result of inappropriate responses to the needs of young people with ASDs.

In contrast, education providers in specialist schools shifted away from individual and ASD related difficulties and highlighted the influence of external factors. For them, the main obstacles faced by young people with ASDs were the results of a system that was not responsive to their needs. They described the challenges their pupils experience when they transition to post sixteen provisions, whether these are colleges, apprenticeships, or employment. These environments are less structured, therefore placing a huge amount of pressure on their pupils.

"I am the sixth form lead so I support learners who transition from year 11 into higher education or further education. I think the main problems that we focus on is a lot, if they are coming from a special school, they are coming from a smaller environment so moving into a bigger one can cause massive anxiety, confusion. Where they have been used to that structure there is a lot less structure in kind of employment, in further education, in different bespoke packages, in internships or apprenticeships. So that lack of structure it causes even more unease and even more anxiety and you almost see a bit of a regression because of that impacting on them and all the strategies they were in place have to be kind of put in place again but in a

more age appropriate way, so yeah I think anxiety and that change is probably the biggest difficulty for the ones that I see"

(Teacher F-specialist school)

Participants focused specifically on the challenges that further education colleges present, as they were a common destination for their pupils. They stressed that the support offered in these colleges does not adequately meet the needs of pupils with ASDs and there is not always the necessary expertise and understanding among their staff. Pupils with high functioning ASDs can perform academically and this creates the impression among education providers that they are progressing as they should. However, in reality they are struggling in this overwhelming environment.

"I think also with high functioning autism in a sixth form provision because there isn't necessary expert knowledge, there is an assumption that they are coping because perhaps they can express themselves or because they are quite academically able and people don't always look further, they just assume a child is just coping, coping, coping and then suddenly a little thing might happen and then- you know- kind of explodes"

(Teacher F-specialist school)

"The assumption that they are coping is almost the assumption that they don't need support. Well you've got all these GCSEs well done, you've got your A stars, you are fine and in college that we link with their level three they don't get support as a standard, doesn't matter what the need is, where they've come from, oh you are fine, you are level three, A level standard, you don't need anything"

(Teacher F-specialist school)

"I am a teacher in (school) but I also have a son who went through (school) and has ended up at college. I think the biggest challenge is going from an environment where everybody gets autism to one where probably nobody gets autism"

(Teacher F-specialist school)

Overall participants identified a gap in the support available in post sixteen provisions that could also discourage pupils from further pursuing and fulfilling their aspirations.

Theme 2: Schools offer life skills support in an individualized and casual manner.

Subtheme 2a: Understanding the specific needs of the pupils and forming strong relationships with them are the cornerstones of a successful approach.

Learning about their pupils and gaining their trust were considered paramount by education providers in their work. In their efforts to meet the needs of their pupils and build relationships with them, they were utilizing a range of personal and professional resources.

Participants, mainly from mainstream schools, described how they were applying their own skills, knowledge, and previous experience in their efforts to teach life skills and support their pupils. What the participants defined as knowledge was their understanding of their individual pupils and their unique needs, instead of a specialized knowledge around ASDs. This aspect was so fundamental that education providers found it difficult to define their actual work with their pupils.

"We endeavour to teach them social skills and that's the very very basics of what we offer but then, what comes naturally is the time that we give them, the understanding that we give them. We learn all about them, they learn about us and we just try and work with them that way. Really, a lot of it is just human nature really, you can't put it into a pot and put a lid on it"

(Teacher F-mainstream school)

"I think with our staff because of their need and the challenges we face we are not just TAs we are more than just TAs or just school staff we are more or less providing them with life coaching, we are a counsellor, we are a mentor, we are more or less similar to being a "sub mum", a substitute mum

bit of a nurse if you can say that, we come under a huge umbrella we juggle so many different parts that we play"

(TA F-mainstream school)

They were also able to successfully utilize their general skills and draw from their previous experiences and roles. For some of the participants, equipping their pupils with life skills was something that were required to do through the various positions they had held within their schools, although it may not had been recognised and defined as such.

"You've always done it as part of your job, it's not like we've not had it in the school, that's the whole point of sixth form learning mentors and school LSAs, it is to model these life skills and talk about social skills and things but I don't think you've thought about it"

(SENCO F-mainstream school)

"It has been on a very ad hoc basis. So, in my office I have sixth form students coming in every single day, I am having trouble with this or this happened, and we talk about it for an hour to get the message across, but now it is exactly that much more structured, much more planned"

(Teacher M-mainstream school)

Participants, mainly from mainstream schools, also highlighted the importance of good communication and support among staff members who work closely with this group of pupils. They believed that the exchange of knowledge and expertise within the team has enabled them to improve their provision and overcome difficulties that have arisen.

"What we do, we are very flexible (…) sometimes I will be working with a student and I will be struggling with the student but I know someone else can do it and I will have to ask my colleague to come and we are so flexible, we work together all the time"

(Teaching Assistant F-mainstream school)

Schools often developed their own resources in order to assist their pupils and these included travel training packages; transitional sixth form to help their pupils adjust to life in a local college. Some of the participants also highlighted their perceived absence of appropriate external resources that could help them to address the needs of their pupils. High functioning pupils were considered to have very specific needs and the participants believed that it was not possible for a widely available resource or program to meet those needs.

"You need to know that back-story to create the right resource, otherwise it could potentially be to generic. Could be more just general skills for people with Aspergers, general skills for people with Autism and that's not our young people. Our young people are very opinionated and very able to articulate what they can and can't do. As we said earlier on they say they can do everything, everything, they can't, so actually how to get on a bus abc isn't putting on what they need they need the xyz what if the bus is late, what if I have not got the right money. They know how to get on a bus, they know when their clothes need to be washed it's just the extras, there isn't necessarily a pack or a resource thing for those extras for high functioning individuals"

(Teacher M-mainstream school)

"And that's the difficulty, because every year and every group is going to be different, the dynamic of the group is going to be different, so we are going to have to change the way we interact with them and the information needed. Ok, we put together a program of a couple of dozen different general activities to do but even then, if the group is really struggling in a different area we haven't covered before then we will cover it, so is difficult to get a resource that is going to cover all that for us if we are not creating ourselves"

(Teacher M-mainstream school)

Participants often asked for assistance from external providers and professionals when they believed that they were better equipped to deliver a training or assist their pupils with some specific issues (e.g. local youth service offers career advice; inviting a police officer to talk about inappropriate texting; consulting psychotherapists on the issue of sexual relationships). However, some of the participants, although they were willing to utilize advice, they were reluctant to bring in someone external to deliver part of the training.

“I had a conversation with some people on Wednesday who are psychotherapists and they have spoken to, they have dealt with, a lot of autistic people in later life and have specific focus on relationships and sexuality. So actually, they might be someone really keen to having further conversation with and I don’t know whether it would be right to bring them into the session because again, our relationship with these boys is such that we can have these open conversations and get on really well with them”

(Assistant Head Teacher M-mainstream school)

As the above quote illustrates, the relationships and the level of trust that the education providers had established with their pupils were the predominant elements of the support. Therefore, they felt uncomfortable with changing the dynamic of their group by inviting professionals that their pupils were not familiar with into the sessions.

Subtheme 2b: Teaching life skills through participation in everyday activities and informal sessions.

All schools aimed to teach their pupils psychosocial and daily living skills. The provided training and support addressed the following areas: social-communication skills; sexual relationships; peer relationships; daily living skills (e.g. travelling independently; cooking; money management; maintaining personal hygiene and appearance; communicating with third parties).

“We have basically divided that [training] into a Life Skills Course with practical tasks. So how to catch a train, how to catch a bus, how to order a coffee in a coffee shop, how to do your grocery shopping, how to cook, how to use the washing machine. (…) So that’s the Life Skills side and in the other side is the social skills. So, we look at covering relationships at the

moment, both relationships with friends, relationships with parents, relationships with the opposite sex, same sex sexual relationships, conversation starters"

(Teacher M-mainstream school)

Most participants perceived the life skills training as integrated into various activities and tasks that pupils have to undertake at school, instead of something distinct and separate. In specialist schools, aspects of life skills training were mostly incorporated into their curriculum, while mainstream schools also reported that their regular curriculum can be slightly modified to meet the specific needs of pupils with ASDs. Participants also described taking part with their pupils in activities organised by schools and external providers and these were indeed considered as part of their life skills training.

"We have set lessons further up in the school. We have life skills sessions where we teach what they need from day to day, from things like personal hygiene through how to use cash machines, writing cheques, cooking, doing their shopping, travelling"

(Teacher M-specialist school)

"*I am taking the year eight sailing on a Thursday. They've got six weeks of sailing and that's really good for their social interaction because they keep mixing the boats up and changing who they are working with"*

(Teacher F-mainstream school)

"Monty the dog, the mentor dog which- allows for- just allows them to calm down because they can take him out for a walk and look after him, take responsibility for him as long as there is an adult with them. So that has worked brilliant hasn't it? They recognize the need for responsibility and accountability and that their actions will impact on the dog and is getting them to transfer those skills from animals to people"

(Form Tutor F-mainstream school)

Specialist schools also emphasized the close connections that had developed with the local community. These connections were providing their pupils with various opportunities to acquire meaningful experience and skills that will prepare them for adulthood.

"We've got as a school a lot of connections. So we've got the (name) trust and we also run the National Citizenship Service which again a lot of our young people took part in that last year and again involved in social action projects, residentials (…) that really sort of helps with their independence and thinking skills and problem solving. So we've got that connection which is really good and we've got connections with places like the local (super-market) where all the food shopping goes down and we've done programs, we used to have a connection with (retailer) they used to go up and do wall papering skills and painting skills (…) So, getting those sort of connections means that we have more opportunity to get them used to the local community and getting out there and not just being confined to a room playing video games (…) We sort of built up their independence by getting them used to the local area in the hope that it becomes less scary when it comes to transition and they have to do these things independently"

(Teacher F-specialist school)

Even in the schools, where more structured training was in place this training often took the form of informal sessions. These sessions were more flexible and they were enabling education providers to accommodate the diverse needs of their pupils.

"A lot of them (sessions) are talking based especially the social skills ones and they are more of a forum than a taught session. So it is a discussion with them asking questions, us giving them answers, us asking them questions about what they think, discussing that between the group people so it is not sort of a presentation based talk session, it's sitting around a table talking about things which so far has worked well we think"

(Assistant Head Teacher-mainstream school)

As the above quote indicates, priority was given to the specific needs of every cohort of pupils rather than following a highly structured program.

Theme 3: Enablers and obstacles in the generalization of life skills.

Subtheme 3a: Encouraging participation in social opportunities but failing to actively facilitate interaction with neurotypical peers.

Education providers in mainstream schools emphasized the significance and the potential benefits from the interaction between pupils with ASDs and neurotypical peers. They were also strongly encouraging their pupils to pursue opportunities that would require them to put their learned skills in practice. These included socializing with other pupils in the school cafeteria; attending school clubs; spending lunch breaks in the mainstream school and not in the unit. However, they could not describe any ways of actively facilitating this interaction within the school. Ultimately, it was down to individual pupils to decide whether they wished to make use of the various social opportunities during the school day.

"We offer a place to explore the norms of socializing and then we expect them to go to the common room, to go to the library and practice what we have discussed, to look out for the things we have discussed (…) whether that happens I don't know, but I would hope that they have taken what we talked about and applying it in social situations"

(Teacher M-mainstream school)

Participants also recognized that most of their pupils would find it a very difficult step and only very few of them would eventually take that initiative. Furthermore, individual characteristics of their pupils had led them to believe that interaction with neurotypical peers may not be the best option for some of the pupils with ASDs.

"I had someone in my form last year who has gone into mainstream full time now because he had a lot of friends in mainstream so he chose to go down

there, but if they don't choose to go down there we don't send them because it can be more that they can cope with"

(Teacher F-mainstream school)

At the same time, they highlighted that the overall environment in the mainstream school may be too chaotic for their pupils and this could actually discourage them from interacting with their peers.

"*They don't mind the odd new student coming in to the centre and they will sort of make friends and they do get a bit nosy and want to know names and things like that, so they will. They just can't do it en masse and I think when you go to mainstream everything is en masse and is just a bit much"*

(Form Tutor F-mainstream school)

Overall, they observed that their pupils preferred to "escape" to the unit during breaks as this was where they felt safe.

"I find in my sevens that they'll be quite friendly and interact quite positively with mainstream children. If they see someone they are in their lessons they are like hi, how are you? But actually, at break and lunch they come back to what is safe and familiar. It almost needs that nudge, have you thought about going to the meeting? so and so for break time"

(Teacher F-mainstream school)

"I think this provision, this particular part is like a safety zone for them, a place where they feel safe and I think a lot of the students feel is part of them, they belong here whereas when they go into the class they don't have that same level of feeling of the secure comfort zone"

(TA F -mainstream school)

Participants were also reluctant to involve neurotypical peers in their training as they were worried that they would not be able to understand the difficulties experienced by pupils with ASDs. Therefore, their presence could discourage the pupils with ASDs from fully participating and benefiting from the training.

“I think if we were to bring in the other students, our boys would not open up with us, we wouldn’t be able to impart the same knowledge, there would be a definite reluctance because they would feel like they are being judged”

(Teacher M-mainstream school)

Schools 2 and 5 were not only providing support to pupils with diagnosis of ASD and EHC plan. They also included those experiencing similar difficulties and education providers believed they could benefit from accessing their provision. School 2 was supporting pupils who were displaying autistic traits but did not have a diagnosis or an EHC plan. School 5 also supported pupils with social and emotional difficulties. According to education providers in school 5, this practice had fostered a culture of acceptance within the school. Pupils without a diagnosis who had spent some time in the unit were more understanding of the needs and difficulties of the pupils with ASDs.

“They are very accepting of autistic children. I think that’s one of our strengths in this school, they don’t judge them, they may have the weirdest behaviour, some of our students have a weird behaviour, but they are very accepting they won’t laugh at them or call them names or anything”

(TA F-mainstream school)

Education providers at the same school also described how they have set up clubs with the aim to teach various daily living skills to their pupils with ASDs and these clubs were also open to all pupils in the school.

"We run a creative club and a cooking club, so we have a mixture of students from the mainstream and our students. I mean obviously our ones get priority like the cooking, you want them to have that life skill because some of them can't hold a knife and fork or butter bread or even like basic things or maybe even cut sandwich- you know- very basic things that you would assume, but then you get a lot of mainstream students who can't do that"

(TA F-mainstream school)

"Well they hear from our students how much they enjoy so other students also want to come and join [the clubs] (….) Yes, they get along very well, so the cooking club is a bit chaotic, but they get on very well"

(TA F-mainstream school)

They believed that these clubs helped to facilitate interaction between pupils with ASDs and their neurotypical peers. However, they described no other strategies that they had in place to further assist their pupils in building relationship with their peers apart from bringing these two groups together. Furthermore, the positive prevailing climate within the school was not sufficient to bridge the distance between pupils with ASDs and their peers. Pupils with ASDs still preferred to spend most of their free time in the unit away from their neurotypical peers.

Subtheme 3b: Maintaining an open line of communication with parents but struggling to build effective partnerships.

Education providers from all the participating schools believed that they had built a close relationship with their pupils' parents. They also stressed the importance of co-operating with the parents and bringing them on board with any of the school decisions regarding the support or training for their children. Education providers were also frequently involved in various aspects of their pupils' family life and this was believed to have reinforced the bond between them and the parents.

In order to support their pupils and their families, education providers were often required to go beyond their immediate responsibilities. One of their main daily tasks, was to give parents a detailed account of their child's school day, since their pupils were not always able to effectively communicate with their parents. They were also making sure that any unexpected problems at school were promptly addressed to ensure a smooth experience for their pupils and subsequently their families (e.g. buy a pupil lunch because they forgot to take their own on a school trip; drive the pupil back home after detention because they missed the bus or the taxi). They were often required to aid their pupils at home and offer emotional support to parents. School 4 was also offering in house training to parents.

"They (pupils) don't communicate with the parents and they'll go home, they really don't understand, the parents don't know, why they are upset or why they are cross or why they had a bad day and the parents almost rely on us to keep them informed and to almost be that translator between school and home"

(Teacher F-mainstream school)

"I think we communicate a lot with parents, so we are very good at that. It's phoning, talking to them on a daily basis, or writing to them on a daily basis, depending on the situation and on the child and the need but I would say overall, we are very much you know, on to that "

(Teacher M-specialist school)

"I've got one particular student who decided that she is not coming into school. I've been up to the house numerous times to get her out of bed and bring her in. If they can't stay for detention because parents can't pick them up then we'll take them home and things like that which we wouldn't do in main school that wouldn't happen, so we support the parents in that way as well"

(Teacher F-mainstream school)

Education providers in specialist schools described occasional tensions between parental views and needs and efforts made by the school to prepare young people for adulthood. They believed it is often difficult for parents to allow more independence to the young people, thus hindering any attempts from school in that direction. They attributed this reluctance on behalf of the parents to two factors. Parents don't see the teaching process that takes place at school. Therefore, they often underestimate the progress that their children have made. Furthermore, parents often struggle to put support for their children in place. Subsequently, they are reluctant to recognise that this support should be removed to allow the young people to make steps towards independence and adulthood. Parental expectations that can either be too high or too low can also affect further progression.

"I think for some of ours [pupils] we find their parents wish to put them in cotton wool and don't view them as having the ability to be independent. One of the things, at sixteen they often require to use public transport, and although we offer travel training and we work with parents they are very reluctant to let their young person reach their potential as an independent. They always, as all parents do, look at what the worse scenario is rather than what they [pupils] can manage, so I think that's also another aspect of, particularly as you said high functioning, been able to be independent is parental care going over the top and not letting them do a bit of risk taking"

(Assistant Head Teacher M-specialist school)

"I think that stems from having those parents possibly having gone through the whole, there is something wrong with my child and the fight to get them EHC plan or to get an assessment, and all the processes they have to go through to fight for their child so once they find, they sort of got that label, it's then difficult to sort of possibly- you know- mentally perhaps for them to kind of go, OK and now we need to get them to the stage where they can be an independent adult, living on their own or travelling on their own and I think to them, because they fought for their child for so long to get them the help, they don't want to relinquish that help"

(Teacher F-specialist school)

"What concerns me is sometimes it's parents who hold them back. I had a very able student and every time he talked about his plans for the future his

mum squashed it and kept saying things like, oh he is never going to leave home, he can't do those jobs, don't put ideas in his head, that sort of thing. He was very able and could have a job, so maybe sometimes it's parents holding them back or worrying out by themselves and things"

(Teacher F-specialist school)

One of the participants, a mother of two autistic young adults, shed a different light on these perceived tensions while validating parental concerns. According to her view, parents and education providers see the young people from different perspectives, which are defined by their distinct roles. While school aims to teach young people life skills that will help them to achieve independence, parents are also worried about the young person's overall vulnerability, something that training is difficult to address. At the same time, the participant made a distinction between acquiring certain life skills and having the ability to lead an independent life, stressing the limitations that are inherent in any training.

"I do feel that some of the parents that we have I can say, oh they are overprotective, but at the same time being a parent then I would have to consider whether my kids will be able to live independently, and I think there is one thing teaching a lot of functional skills, like cooking and using the washing machine and making a phone call, but in my experience a lot of the difficulties have to do with their vulnerability, of how vulnerable they are in society and that they can be taken advantage of or get themselves into situations"

(Speech and Language Therapist F-specialist school)

Participants in all focus groups emphasized the importance of working closely with parents and how crucial parental support was in helping their pupils achieve better outcomes in life. However, the majority of them did not attribute any agency to the parents and did not describe any parental influence in the training and support they offered to their pupils. In the few instances where participants talked about parental input, they referred mainly to the discussion and exchange of strategies used between school and home.

“[pupils] know you and home have got each other’s backs, and home will support what you’ve said and likewise if home said no that you’ll support them and they know they can’t push it”

(Teacher F-mainstream school)

The only possible exception were education providers in school 2 who were regarding parents as experts when it comes to their children and believed that parents can contribute to the training.

“There isn’t anybody else that can feed into that (training) other than the parents they can feed in things they can give some, oh actually if you approach it like this with them that would help”

(Teacher M-mainstream school).

Overall, parents were either needed to be brought on board with decisions made by the school and work along with the education providers or needed to be supported. In some extreme cases, they were unintentionally obstructing their child’s progression.

Theme 4: Successful outcomes require a more holistic approach.

Subtheme 4a: Allocating more resources to schools while also acknowledging the imitations of the support that they can offer.

Education providers felt confident in their work and they believed that they had the necessary abilities and skills to support their pupils. They didn’t express any strong requirements for additional training. However, they voiced the need for more available resources and services for their pupils in adulthood.

Education providers also expressed the request for more available means as they often had to undertake a lot of additional tasks. Some of them were supporting pupils without EHC plans in addition to those who were entitled to the support offered in the units. Others were working in schools that were not formally recognizing the life skills training and support they were offering as part of their roles. All these had taken a toll on the participants. Under these circumstances, they were often required to go over their allocated tasks and take on more responsibilities, making their own personal sacrifices. A few participants, rather jokingly, expressed the need for emotional support and counselling, indicating however that they often take on too much.

"Every time we have meetings we will be reminded to support those students [without EHC plans] as well and when they come to the provision we don't say you don't belong to us, we have to take them in. So that's why we need a lot of support. We still have to reach these children who don't have statement, their parents don't know maybe where to go but we still support them"

(TA F-mainstream school)

"It's the time issue because SENCO (name) is very good and supports us in doing it. She is our boss, she lets us pretty much do what we want but it's not one of our job roles really, is something that we found time to do, a lot of our meetings about this are after school in our own time (…) it hasn't gain this financial leg yet I think, maybe in the future the school will recognize it as an important and offer to pay for it in a way they are supporting it"

(Teacher M-mainstream school)

Education providers from specialist schools voiced their desire for the development of a residential unit within the school. This unit will enable pupils to experience their first steps into independence within a safe and controlled environment. Pupils will have the opportunity to actually put to practice all the necessary skills that are being taught in a meaningful, safe context. They believed that this experience could be crucial in preparing them for independent living. The lack of funding and resources is what stops schools from currently offering this type of supported living.

"I think having the financial ability to set up like a flat where they can go and live for a month and they are, yes supported, but they are away from their

parents and they actually need to do things for themselves (…) so then you will have to do all those things. Meals are not provided for you, you actually have to make them, and then you are going out and you need to make a lunch because otherwise you are going to be hungry and your clothes aren't going to wash themselves and no one is going to put them out for you. You have to do all those things and you have to go and you have got to plan and you have got the budget and this is how much money you have and if you run out what's going to happen. So yes, in an ideal world I would love to- you know- for something like that to actually happen"

(Assistant Head Teacher F-specialist school)

Participants, mainly from specialist schools, also emphasized the necessity for their pupils to have long-term support during their adulthood. They believed that schools were successful in supporting and helping their pupils to learn essential skills. However, their efforts alone were not enough to guarantee a successful outcome in adulthood, as the support must continue beyond school age.

"(…) It doesn't seem to be enough out there to pick up young people when they are sort of older at 30 (…) and there is nobody encouraging them to do things on their own, nobody encouraging them to get a job, so they get into a trap, so I think that's something that definitely is missing"

(Assistant Head Teacher M-specialist school)

"What is out there post university? There should be some sort of adult support service for those who still technically have an EHC plan that just need that modelling, that support, just to get on to and whether that's done through something like the job centre, whether that is a charity, I don't know but there should be something there for that transition"

(Teacher F-specialist school)

They have also described that they have seen services disappearing over the years, leaving significant gaps in the provisions, while there are no alternatives. These developments have led them to worry about their pupils' prospects once support is not available any more.

Subtheme 4b: Creating an environment that can foster communication, exchange of ideas and understanding.

Improving communication between schools, other stakeholders and the public was another aspect that was highlighted by participants. Creating an environment where not only it would be easier to exchange ideas and expertise among interested parties but it would also educate and inform the public about ASDs could significantly assist their pupils in achieving their goals and aspirations.

Education providers in mainstream schools expressed the need for guidance, advice and developing connections with other schools in order to exchange expertise and ideas. Not having links with other schools has often led them to feel that they are working in isolation and there was no support available to them.

"I think we are keen to see what other schools are doing, other colleges are doing with life skills (…) We want advice, don't we? That's one of the things, although I don't feel we've ever gone out of depth with these things. I think, like I said earlier, we very much looking to see what other people are doing and how we can improve on that from outside sources, from other schools"

(Teacher M-mainstream school)

Better communication between schools, post sixteen provisions and other stakeholders was also a priority among education providers in specialist schools. Participants felt that they are able to assist their pupils with the transition to further education. However, they were often unable to support them as this process does not always allow for proper preparations to take place.

"We try to do the best to our ability to transition them but the issue that I find is actually we don't get the confirmation that they secured the place until a

week before they are due to leave. I mean last year we had to transition students within the last two or three days and actually take them to the new school, what preparation is this?"

(Assistant Head Teacher F-specialist school)

Finally, raising awareness among society and particularly potential employers was thought to be crucial in helping their pupils achieve their goals in adulthood.

"*I would like to educate the world really. I would love to set up a program where we take out autistic learners who are successful into businesses and get them to give presentations about autism and how actually I am autistic and I am still employable (…) I think you can have a program set up nationwide and I do think it needs to be nationwide where people, autistic people, who are perfectly capable of holding down a job, function in society, go into places and give presentations, I am autistic I am a perfect example of what can be done(..)"*

(Teacher F-specialist school)

Increasing understanding around the condition and focusing on what young people can contribute with adequate support, were necessary in helping to reach their full potential.

5.6 Discussion

The aim of the study was to investigate life skills training and support that is available in UK schools for high functioning pupils with ASDs and explore the views of education providers regarding current provisions and their recommendations for future improvements. This was the first study to look specifically into life skills provision in schools for high functioning pupils with ASDs and the first to explore the views of education providers exclusively on this issue.

Education providers in both mainstream and specialist schools felt confident in supporting their pupils and did not express any strong requirements for additional training. Those in mainstream schools believed that they were able to apply their general skills successfully when working with their pupils. Some also reported that they had extensive experience of supporting ASDs pupils, although this was taking place in a more informal basis. These findings appear to contradict previous studies that had highlighted that teachers, particularly those in mainstream schools, lack the competence to teach and manage the behaviours of their pupils with ASDs (Able et al., 2015; Lindsay et al., 2013; Robertson et al., 2003). These studies stressed the need for ASD training among education providers (Able et al., 2015) whereas findings from this present study suggest that they consider themselves to have adequate expertise. However, when looking closer into some of the participants' accounts, some doubts are casted over their perceived confidence.

Education providers appeared to be working in a more informal, ad hoc and unstructured way rather than implementing more concrete training programs. They believed that the specific and unique needs of their pupils justified this approach. Some of the participants also expressed the view that there are no training packages that can meet the needs of their pupils. Therefore, what is currently stopping them from applying research-based and evidence-based programs are both their limited knowledge and their belief that an unstructured approach is more beneficial.

In the present study, education providers admitted that what enables them to support their pupils was a very good understanding of their needs and the strong relationship they had built with them. Similar views had been expressed by staff members in residential care settings who highlighted the need to understand service users (Bradshaw & Goldbart, 2013). They believed that this could be achieved by spending time with them, understanding their needs, and how to best support them.

Literature has listed several obstacles regarding the acceptance and implementation of evidence-based practices by education providers. Although a few important factors come at play (characteristics of the host organization; costs; lack of program readiness) the behaviour of education providers has also been identified among them (Walker, 2004). According to Broadman et al., (2005) education providers in special education expressed concerns that training programs may not always meet the diverse needs of their pupils.

Another possible issue in the provision of life skills support was the limited use of generalization strategies. It appears that schools are failing to fully involve the two groups of people, peers and parents, that could assist their pupils with practising newly learned skills. Education providers in mainstream schools were assisting their pupils to learn the skills that will enable them to build and maintain peer relationships. They were also taking every opportunity to encourage them to interact and socialize with their peers and fully participate in various social opportunities. However, they were not actively facilitating peer interactions. This was not attributed to any difficulties related to their own skills and abilities or other factors within the school. Education providers did not perceive that support with social skills and peer relationships could also include the active engagement and participation of neurotypical peers.

The involvement of parents also presents challenges in both mainstream and specialist schools. Participants' believed that they maintain good relationships and cooperate closely with parents. However, they provided several examples of parents not understanding nor endorsing the support employed by the schools, therefore making it difficult for pupils to further develop and practice behaviours and skills in natural settings.

With limited opportunities available for generalization, education providers “hoped”, as one participant noted, that their pupils will apply the skills they were taught in social situations. This attitude resembles the “train and hope” method of generalization which has been described in the literature of Applied Behaviour Analysis (Stokes & Baer,1977). According to this approach, when a skill is learned or a behaviour is changed during training, generalization across settings or times is not actively pursued or explicitly programmed but rather it is hoped that it will occur.

Overall, participants showed limited knowledge and application of evidence-based practices. In some occasions, they described limited connections with other schools/services and, in general, limited input from parents in the training. What they considered quite useful in their work was the communication and the support among their colleagues and the exchange of advice and expertise. Since external influences on the training are minimal, the only sources of validation are team members who are working in the same environment and are more likely to hold the similar views. Under certain circumstances, it is possible that within this closed system, practices that may not be beneficial or effective are being reinforced and reproduced making them more resistant to change.

Regarding more specific preparations for adulthood transition, what became apparent was the disparity of resources that education providers in specialist and mainstream schools could utilize. Specialist schools had developed various links with the local community and they were in a better position to seek external advice and support. As a result, they offered a number of additional opportunities to their pupils, with the work placements being the most significant. These were not available to the same extent in mainstream schools, although their pupils could possibly also benefit from similar experiences.

There were also striking differences between education providers in mainstream and specialist schools regarding their perceptions about the obstacles faced by their pupils. Participants in specialist schools attributed these to a society which does not understand and is not ready to accommodate their needs. In contrast, participants in mainstream schools highlighted the ASD related difficulties and how these can become an obstacle during transition to adulthood. Individuals with autism have highlighted a social model approach which emphasizes the economic and social barriers experienced by people with disability (Oliver 1996; Chapell, Goodley, & Lowthom et al., 2002). They are trying to raise awareness through various initiatives such as self-advocacy groups (e.g.www.autisticadvocacy.org) while promoting the tools and supports they need to access education, employment and participate fully in the society. Staff members in specialist schools, possibly because they are immersed in ASDs, appear more likely to adopt that perspective than staff members in mainstream schools. The latter, although they are working closely with pupils with ASDs, cannot escape the comparisons with neurotypical peers, therefore focusing on ASD related challenges.

Education providers in this present study favoured an individualized approach to training and support and despite the drawbacks, the perceived benefits cannot be underestimated. This finding could highlight that one of the main factors that can assist education providers in their efforts to provide life skills training and support is not only a pre-existing knowledge of the condition or relevant training. As participants in the study stressed what is equally important is having a good understanding of the needs of the pupils they work with. This finding could also indicate the possible significance of the life skills training being delivered by someone who naturally encounters the young people. This is something currently absent from the clear majority of the life skills interventions designed for this population.

Only a minority of those interventions were delivered within schools (Argott et al., 2008; Clark et al., 2016; Laugeson et al., 2014;Minihan et al., 2011 Pahnke et al., 2014) and only in two interventions (Laugeson et al., 2014; Minihan et al., 2011) the delivery agent was a professional who worked within the school and has regular contact with pupils.

The involvement of neurotypical peers in the support appeared to be problematic in practice, however it is also poorly addressed in the literature. Guidelines for younger children with ASDs suggest using peer buddies and co-operative groups in a mainstream setting to ensure inclusion in peer activities (Dahle, 2003). Furthermore, they stress that children should not be left alone during social interaction as they will not seek out their peers without help (Dahle, 2003). In interventions designed for older populations, peers are rarely involved in life skills training with only a few exceptions (McMahon et al., 2013; Minihan et al., 2011; White et al., 2010). Parents are usually responsible for bringing together their children with their peers in sessions outside of the training, but these sessions are poorly described in the literature (Gantman et al., 2012; Hill et al., 2016; Laugeson et al., 2009, Laugeson et al., 2012; Laugeson et al., 2014; Laugeson et al., 2015; Lordo et al., 2017; Schohl et al*.,* 2014; Yoo et al., 2014).

Nevertheless, it has been suggested that pupils with ASDs are more likely to spend their break and lunchtimes alone, and engage in less interaction with their peers than those with other or no SEN (Able et al., 2015; Humphrey

& Symes 2011). Furthermore, more socially able pupils with ASDs reported more bullying and victimization in mainstream schools (Rowley et al., 2012).

Participants stressed the need for support services in adulthood for individuals with ASDs. They believed that no matter how successful schools were in equipping young people to deal with the demands and challenges of adult life, long term support is essential and needs to be available. These views were expressed mainly from education providers in specialist schools and could again reflect their alignment with the social disability model.

However, it is possible that shortcomings in the current school provisions such as limited application of concrete life skills programs and generalization opportunities may have further increased the requirements placed upon adult services. As a result, education providers viewed the continuation of support as essential.

Education providers in specialist schools suggested the addition of residential units within schools. They believed that this development will complement their existing efforts to prepare their pupils for adulthood. Although there are possible benefits from this approach, current provision of life skills should be further improved to ensure that it will lead to the desired outcomes.

Absence of concrete generalization strategies may transform these units into artificial environments where pupils learn skills however, they are not able to transfer them in real life situations. These units can also create more barriers between young people with ASDs and their peers in case that there is not a clear plan on how to create opportunities for socialization and interaction. If these issues are not addressed, it is possible that the drawbacks will undermine any potential benefits.

5.7 Implications for research and practice

It appears that both specialist and mainstream schools are the main providers of life skills training for their pupils. As a result, there is expertise available among staff and support already in place. Therefore, efforts should strengthen their existing capacity to offer high quality life skills training for their pupils. Support should be directed towards encouraging education providers to consider the benefits of applying more structured and evidence-based practices. Meeting the individual needs of the pupils is a crucial element of a successful intervention. However, this appears to have become the sole focus in the approach adopted by education providers interviewed for this study and is currently stopping them from implementing more structured and potentially more effective practice.

One aspect that currently seems to be absent from the life skills provision in schools are any steps that would facilitate interaction between pupils with ASDs and their neurotypical peers. Peer mentoring could possibly assist in that direction, but more research is needed, especially within a school setting, regarding benefits and drawbacks before implementation. Communication and co-operation with parents should also be improved and become deeper and meaningful for both sides, as parents' significant role to play in the training is not fully utilized.

Participants called for improvements within the wider system. One area that was identified was communication between schools and other stakeholders. Creating more formal local partnerships and forums between mainstream and specialist schools and organizations that support individuals with ASDs could be a way forward. This step could significantly assist mainstream schools in establishing deeper connections with their local community.

Furthermore, specialist schools could function as hubs for autism support within their community. They currently provide training to pupils, parents and teachers. Both specialist schools that took part in the study expressed the need for a residential unit within school. This option could be further explored as part of a broader discussion which seeks to improve all aspects life skills support.

5.8 Strengths and limitations

This was the first study to investigate the school provision of life skills training for high functioning pupils with ASDs in the UK. It included a variety of schools, both mainstream and specialist, that cater for this population and had experience of supporting pupils with ASDs with life skills. The inclusion criteria allowed the study to provide a better understanding of life skills training that takes place in schools, rather than explore perceptions and views among education providers who may or may not have experience of offering training and support.

The study also had several limitations. It included a small number of schools and education providers. Trying to recruit schools with expertise in the field had certain drawbacks as many schools did not meet the inclusion criteria. Recruitment throughout the study was slow and a small number of schools participated. Most of the schools which were approached did not make any contact with the researcher. Therefore, it is not possible to know what stopped their participation or what could have been improved to increase recruitment.

Only two schools replied out of those who were approached but did not participate. Both of them were specialist schools. Their feedback was that they did not meet the study inclusion criteria because they did not cater for pupils with ASDs without intellectual disability. This could be one of the reasons that had resulted in low participation, especially among specialist schools. Increased workload could have also affected recruitment as schools were struggling to fit in the focus group among their busy schedule. Long waiting times that were required to arrange the focus group with participating schools as they were busy with other commitments could be an indication of a more widespread phenomenon.

Furthermore, selection criteria for education providers within each school required those who work closely with the pupils and they have the task of supporting them with life skills. Again, this meant that most staff within mainstream schools did not meet the criteria. This resulted in a small number of participants per focus groups per mainstream schools, with three-four participants in each group.

Although the aim was to have minimum three participants in each focus group, it was not possible to meet this requirement in one instance. In school 3, one of the potential participants was not able to attend due to illness. This was only communicated to the researcher upon arrival at the school. All preparations had been made and therefore it was not possible to reschedule the focus group, which took place with only two staff members. Although it was possible to maintain a conversation with the two participants, the small number of participants undoubtedly resulted in a limited pool of views and ideas.

Furthermore, focus groups were subjected to strict time limitations. Focus groups took place during or after the end of the school day. As a result, professionals had either other engagements or their working day was over. In most cases, it was not possible to run over the allocated time, which was 45 to 60 minutes. As a result, the researcher did not have the opportunity to explore certain issue in more depth as the limited time would not allow it.

5.9 Conclusion

Findings revealed that there is expertise among education providers and efforts are being made to tailor the support to the individual needs of the pupils with ASDs. The findings also highlighted some shortcomings in relation to the application of more structured programs and the use of generalization strategies. Although participants did not express any requirements for additional training, they asked for improvements in the wider system such as allocation of more resources to schools and better communication between schools and other stakeholders.

5.10 Rationale for next chapter

This was the second qualitative study of the thesis, investigating life skills training among schools in the UK and exploring the views of education providers. The aim of the first qualitative study (refer to Chapter 4) was to explore the views of parents and young people regarding current provisions and their needs for future training. Findings from both studies revealed similarities and differences between the views of parents and education providers. The aim of the next study is to compare the views of parents whose children attend different types school and education providers who work in similar establishments regarding: life skills challenges experienced by young people with ASDs; optimism regarding outcomes in adulthood; satisfaction with school support; desired training and support.

Chapter 6 : Cross-sectional survey

6.1. Chapter Summary

Background: In Chapters 4 and 5, participants described prominent ASD related life skills challenges; expressed their views on school provision and identified various areas that life skills support should target along with their preferred types of support. The aim of this cross-sectional study was to investigate and compare the views and experiences of parents whose children attend different types of schools and education providers who work in similar establishments in relation to: **a)** life skills challenges that young people with ASDs experience; **b)** expected outcomes in adulthood; **c)** satisfaction with life skills support that is available in schools; **d)** types of support that they consider beneficial. Specific hypotheses were also tested.

Method: Data were collected through, two anonymously administered questionnaires, one for parents and one for education providers, which were designed specifically for this study. Data from Likert-type rating scales, multiple choice, yes/no and ranking responses were analysed, and non-parametric tests were used to test hypotheses and make comparisons between the groups of participants. A limited number of open questions were analysed with content analysis.

Results: Parents did not appear very satisfied with life skills support offered in their schools. Parents whose children attended specialist schools, were among the most satisfied. On the contrary education providers expressed high levels of satisfaction with the support offered by their schools. However, both groups prioritized similar areas of life skills support, favoured individualized approaches and identified mentoring//befriending among their main preferences.

Conclusion: Better communication between parents and education providers may contribute towards improving the life skills support offered by schools. Individualized approaches, including mentoring/befriending, could be further investigated as they appear to be considered beneficial by both parents and education providers.

6.2. Introduction

Pupils with an ASD diagnosis in the UK can attend various educational placements including mainstream schools, specialist schools or schools and units specialized in ASDs (Jones, 2002). Some of these pupils with more complex needs will receive an EHC plan (DfE, 2015). There are a number of factors that influence whether a pupil attends any of the above placements such as availability, funding and preferences from local educational authorities (Jones, 2002). In most cases, specialist schools and units which specialize in ASDs will only accept pupils with an EHC plan.

A report by the House of Commons Skills and Education Committee (2006), highlighted that schools often struggle to provide adequate support for pupils with ASDs. As a result, these pupils may slip between the cracks of an educational system that is not equipped to meet their needs. These failings are also the cause of widespread distress among parents. Parental satisfaction with school placement has been the focus of many investigations that reveal a rather complicated picture (Barnard et al., 2000; NAS, 2017; Parsons, Lewis, Davison, Ellins, & Robertson, 2009a; Parsons, Lewis, & Ellins, 2009b; Starr & Foy, 2012; Whittaker, 2007).

A UK based study explored satisfaction with school placement among parents of children with learning difficulties and disabilities, including those with ASDs (Parsons et al., 2009a). Findings revealed that parents in general had positive experiences and views and they believed that schools were providing adequate support to their children. Similar findings were reported by Parsons et al., (2009b), who compared views of parents of children with and without ASDs. Again, all parents rated many aspects of school provision positively and they reported very similar views and experiences. In another UK based study by Whittaker (2007), the majority (61%) of parents rated themselves as being *'satisfied'* or '*very satisfied'* with their educational provision. According to an older report by the NAS published in 2000, 73% of parents were satisfied with the education that their child was receiving (Barnard et al., 2000).

However, a closer look into some of the findings can reveal a slightly different reality with a high number of parents having serious concerns about the quality of provision being offered to their children. In Whitaker (2007), almost 40% of parents rated themselves as being dissatisfied with their school provision. In a more recent report by the NAS, 40% of parents believed that their school does not meet their child's needs (NAS, 2017). The comparison of the two reports from NAS published in 2000 and 2017 shows that the percentage of parents who are dissatisfied with their child's education and support has increased within these 17 years. This could reflect that little has happened in terms of actual change, despite shortcomings being widely recognized and documented.

Similar findings were reported in a study by Starr and Foy (2012) conducted in Canada. Although a slight majority of the parents was satisfied with their child's education, nearly half were either *"somewhat satisfied"* or *"dissatisfied"*. On top of that, life skills provision also appears problematic with parents not being satisfied with the training and support that their children are receiving (Barnard et al., 2000).

A common finding among many studies is the different satisfaction levels of parents whose children attend specialist and mainstream provisions. In Parsons et al. (2009a), parents whose children were attending specialist schools appeared to be amongst the most satisfied. According to Whitaker (2007), levels of dissatisfaction with mainstream provision were much higher than for special school or unit-based provision. Less than one in ten of the parents whose children attended the mainstream types of provision described themselves as *"satisfied"*. According to the NAS, parents whose children attend an ASD specific provision were twice as likely to be *'very satisfied'* than those parents whose children attended a mainstream provision (Barnard et al., 2000). Similarly, Renty and Roeyers (2005) reported that parents whose children attended a specialist school were more satisfied with the provision in comparison to those who were receiving general education.

It has been suggested by Parsons et el., (2009$_b$) that high levels of satisfaction among parents whose children attend specialist schools may be attributed mainly to the personal and social aspects of support rather than academic achievement. Parental aspirations may also play a role in satisfaction with school. According to Casey, Davies, Kalambouka, Nelson, and Bolye, (2006) parents of children with emotional and behavioural difficulties who attend mainstream schools have higher aspirations regarding educational achievement and employment than those parents whose children attend specialist schools.

There is evidence that satisfaction with school placement is reduced as children move to secondary schools and further education, as these provisions are considered less able to meet the needs of pupils with ASDs (Barnard et al., 2000). According to Starr and Foy (2010), the percentage of satisfied parents was considerably low in secondary schools (33%) and the most satisfied were the ones with children in kindergarten or in first years of primary school.

Studies have also identified several factors that contribute towards greater dissatisfaction among parents. These include: failure of the schools to meet the needs of their children; failure to understand their children; lack of knowledge regarding ASDs; ineffective communication and collaboration with parents (NAS, 2015; Starr & Foy 2007; Whitaker, 2007; Zablotsky, Boswel, & Smith, 2012), although parents of pupils with ASDs are more likely to be involved with the school (Zablotsky et al., 2012).

According to a report by the NAS, only 27% of parents whose children attend mainstream schools reported that their child's teacher could adjust their approach and teaching materials (Batten & Daly, 2006). This extends to more senior and experienced members of staff, with only 23% of parents being satisfied with SENCOs understanding of ASDs (Batten & Daly, 2006).

Furthermore, only 30% of parents of children in mainstream education are satisfied with the level of understanding of ASDs across the school (Whitaker, 2007). More importantly, parents often attribute the absence of appropriate strategies to the failure of staff to grasp the nature of their children's needs rather than viewing this as the result of resource, organisational or curricular constraints (Whitaker, 2007).

It is worth noting that parental satisfaction alone does not guarantee that their children's needs are met as parents may not always be in possession of all the facts (Whitaker, 2007). However, although parental satisfaction with school provision has been widely investigated, it was not possible to locate studies exploring the views and satisfaction of education providers with their school's provision. Several studies have explored perceived competence among education providers regarding their abilities to support pupils with ASDs (Able et al., 2015; Gregor et al., 2001; Jones, 2006; NAS, 2017; Leach & Duffy, 2009; Lindsay et al., 2013; Robertson et al., 2003).

Studies have highlighted that education providers struggle to teach and manage the behaviours of their pupils with ASDs (Able et al., 2015; Jones, 2006; Leach & Duffy, 2009; Robertson et al., 2003) and the lack of adequate training (Gregor et al., 2001; Lindsay et al., 2013). However, one study contradicts the above findings. According to Humphrey and Symes (2011) teachers who took part in their study felt that they were able to cope with behaviours associated with ASDs.

Parents have also identified various areas of priority regarding school placement. These include: understanding of the condition; understanding the pupil; improving social skills; quality of relationship between home and school and communication (Whitaker, 2017). Parents have consistently expressed the requirement for school staff to understand and meet their children's specific needs.

However, teachers and parents may hold different views regarding the needs of their pupils and children respectively as according to Mayes and Lockridge (2018), teachers tend to report fewer symptoms in pupils with ASDs than mothers. It is possible that these different perceptions may actually affect the training and support that schools consider necessary and appropriate for their pupils while parents may not view this same training and support as being adequate or satisfactory.

6.3 Research aims and hypotheses

Various studies have investigated parental satisfaction with school provision in a more holistic sense (Parsons et al., 2009$_a$; Parsons et al., 2009$_b$; Starr & Foy, 2007; Zablotsky et al., 2012; Whitaker, 2007). However, none of these studies focused specifically on life skills training and support, although parents have reported that these aspects are among their main concerns (Barnard et al., 2000).

The aim of this cross-sectional study was to investigate and compare the views and experiences of parents whose children attend different types of schools and education providers who work in similar establishments in relation to:

- The life skills challenges that young people with ASDs experience.
- Expected outcomes in adulthood for the young people.
- Satisfaction with life skills training and support that is available in the school.
- Types of support that they consider beneficial.

In order to acquire a more comprehensive understanding regarding life skills provisions in UK schools the study aimed to capture the views of both parents and education providers.

Eight alternative hypotheses were formulated for this study:

Hypothesis$_1$

Parents of young people with ASDs who attend mainstream schools and further education colleges will rate life skills challenges lower than parents of young people who attend specialist schools. Attending a specialist school requires an EHC plan, which is considered an indicator of the severity of ASD symptomatology. Therefore, it was expected that young people in specialist schools will experience more significant life skills challenges than those in mainstream schools and further education colleges.

Hypothesis$_2$

Parents of young people with ASDs who attend mainstream schools and further education colleges will be more optimistic about outcomes in adulthood than parents of young people who attend specialist schools. A previous study (Parsons et el., 2009$_b$) have shown that parents of pupils with emotional and behavioural difficulties who attend mainstream schools have higher aspirations than those parents whose children attend specialist schools.

Hypothesis$_3$

Parents of young people who attend specialist schools will be more satisfied with the support they had received around life skills than parents of young people who attend mainstream schools and further education colleges. Previous studies (Barnard et al., 2000; Renty & Roeyers, 2005; Whitaker, 2007) have reported greater satisfaction levels among parents whose children attend specialist schools.

Furthermore, these high levels of satisfaction among parents can be attributed to personal and social aspects of support. Therefore, it was expected that specialist schools will provide more substantial support around life skills compared to mainstream schools and further education colleges, thus increasing parental satisfaction.

Hypothesis$_4$

Education providers in mainstream schools and further education colleges will rate life skills challenges of their pupils lower than education providers in specialist schools. Attending a specialist school requires an EHC plan which is considered an indicator of the severity of ASD symptomatology. Therefore, it was expected that the young people who attend specialist schools will experience more significant life skills challenges than those who attend mainstream schools and further education colleges.

Hypothesis$_5$

Education providers in mainstream schools and further education colleges will be more optimistic about outcomes in adulthood than education providers in specialist schools. It was expected that young people who attend mainstream schools and further education colleges will experience less significant life skills challenges. Therefore, their education providers will be more ambitious about their future and will feel more optimistic about outcomes in adulthood than education providers in specialist schools.

Hypothesis$_6$

Education providers in specialist schools will be more satisfied with the support their school offers around life skills than education providers in mainstream schools and further education colleges. Previous studies have reported that specialist schools focus more on personal and social aspects of support. It was expected that specialist schools will be better equipped to provide support around life skills thus, leading to greater satisfaction levels among their staff.

Hypothesis$_7$

Education providers in specialist schools will feel more confident in supporting their pupils with life skills than education providers in mainstream schools and further education colleges. It was expected that specialist schools will be better equipped to provide support around life skills, thus, their education providers will trust their abilities to support their pupils more than education providers in mainstream schools and further education colleges.

Hypothesis$_8$

Education providers in mainstream schools and further education colleges will rate resources that they use lower than education providers in specialist schools. Specialist schools were expected to be better equipped to provide support around life skills. Therefore, education providers in specialist schools will make better use of more resources. As a result, they will provide higher ratings than education providers in mainstream schools and further education colleges who were expected to use fewer resources.

6.4 Method

6.4.1 Sampling method and inclusion criteria

A non-probability purposive sampling method (Toncgo, 2007) was used to recruit participants who shared common characteristics. There were two phases in the recruitment process. The first was the identification and recruitment of gatekeepers. These included schools that catered for pupils with ASDs without co-occurring intellectual disability and organizations that provided services to young people with ASDs and their families. Gatekeepers who agreed to participate were then requested to distribute the questionnaires to parents and members of staff. Organizations, schools and participants had to meet certain inclusion criteria to be included in the study.

Gatekeepers

Gatekeepers had to meet at least one of the following inclusion criteria.

- Secondary or further education establishments that cater for pupils with ASDs in the age group 11-18 years without co-occurring intellectual disability.
- Organizations that provide services to young people with ASDs and their families.

Parents

Parents had to meet all the following inclusion criteria to be part of the study.

- Parents/carers of at a least one young person in the age groups 11-18 years diagnosed with ASD without co-occurring intellectual disability.
- The young person must attend a secondary or further education establishment that caters for pupils in the age group 11-18 years without co-occurring intellectual disability.

Education providers

Education providers had to meet all of the following inclusion criteria to be part of the study.

- Professionals and support staff who work in a learning support or educational capacity.
- Professionals and support staff who work in secondary or further education establishments that cater for pupils with ASDs in the age group 11-18 years without co-occurring intellectual disability.

6.4.2 Recruitment

Ethical Approval for the study was obtained from the Medway School of Pharmacy Research Ethics Committee (Appendix D_1). Recruitment procedures are described separately for schools and organizations.

6.4.2.1 Schools

An Invitation Letter (Appendix D_2) was e-mailed to the five schools that took part in the second study (refer to Chapter 5). The researcher had already established contact with a senior member of their staff. Additionally, five more secondary schools that met the inclusion criteria were identified through personal contacts. The schools were located in Kent. An e-mail was sent to these five schools.

The e-mail included an Invitation Letter (Appendix D_2), a Gatekeeper Information Letter (Appendix D_3), a Gatekeeper Consent Form (Appendix D_4), a Participant Invitation /Information Letter (Appendix D_5), the questionnaire for parents (Appendix D_9), the questionnaire for the members of staff (Appendix D_{10}) and a Social Validity Form (Appendix D_{11}). Different Invitation/Information letters were designed for mainstream and specialist schools in order to describe more accurately the recruitment procedures. Documents designed for specialist schools are included in the Appendices.

Schools were given the option to receive an online link to the questionnaires, paper questionnaires or both for their members of staff, in an effort to increase the response rate. If they opted for the online questionnaires, they were also requested to send reminder e-mail two weeks after the beginning of the study. Only online questionnaires were available for parents, since e-mail was the most common and convenient method of communication between schools and parents. Schools were also requested to send a reminder e-mail to the parents two weeks after the beginning of the study.

6.4.2.2 Autism Organizations

A list of organizations that met the inclusion criteria in England was created. Organizations in Scotland, Northern Ireland and Wales were excluded, as local governments may have regulated educational provisions differently. Exploring those aspects was beyond the aims of the study. Different combinations of the keywords: “autism”; “ASD”; “parent”; “support”; “organization”; “UK” were used in online searches to identify organizations that met the inclusion criteria.

The list included 43 organizations and parent support groups. An e-mail was sent to all the organizations and support groups and it included an Invitation Letter (Appendix D_6), a Gatekeeper Information Letter (Appendix D_7), a Gatekeeper Consent Form (Appendix D_8), a Participant Invitation/Information Letter (Appendix D_5), the questionnaires (Appendices D_9, D_{10}) and the Social Validity Form (Appendix D_{11}).

If a gatekeeper agreed to participate they could then decide on their preferred way of making the questionnaire available to their members. They could either advertise the questionnaire on their websites/newsletters or forward this directly to their members. If the gatekeeper decided to forward the questionnaire directly to their members, they were requested to send a follow-up e-mail two weeks after the beginning of the study. Only electronic questionnaires were utilized with organizations and support groups. E-mails and newsletters were the preferred and most convenient methods of communication with their members, who would often reside in a wide geographical area. The researcher also forwarded the links to the online questionnaires to parents and professionals who were her personal contacts and met the study inclusion criteria.

6.4.3 Ethical considerations

Ethical issues when conducting surveys can be similar to those encountered in qualitative research. In this study emphasis was placed mainly on maintaining confidentiality, acquiring informed consent and considering the sensitive nature of the topic, avoidance of harm (Kelley, Clark, Brown, & Sitzia, 2003; Roberts & Allen, 2015).

Confidentiality and anonymity

Reassuring participants of their confidentiality and anonymity are essential in every research project, however there were some additional considerations with this study. Education providers and parents were asked to rate aspects of life skills provision available at the school that they worked or was attended by their child/ren. Some of the participants would have received information about the study directly from these schools. Therefore, the Information Letters clarified to participants that their responses were completely anonymous, and schools would not be able to identify individual participant responses.

Informed consent

When accessing the online questionnaires, participants were initially directed to the Information Letter where they were required to confirm that they had read it before commencing. If paper questionnaires were used, an Information Letter was included in the packs given to the participants. The Information Letter clearly explained to the participants that, by returning or submitting the completed questionnaire, the participant was consenting to participate in the study. At the end of the questionnaires the following statement was added: *“By completing and returning this questionnaire, you* *are giving your consent to be part of this study and for your data to be used as described in the participant information letter".*

Avoidance of harm

Questionnaires focused on life skills challenges experienced by the young people with ASDs and perceptions of support. The nature of the subject may had given rise to feelings of distress among participants. This acknowledgement resulted in the inclusion of relevant statements in the Information Letter to warn participants of possible adverse effects. Statements were added to the Information Letter to clarify to the participants that: a) all their responses would be anonymous; b) participation is voluntary. Participants were also advised that in case they experienced distress they could visit the site of the NAS where they would find guidance and information on services they can access.

6.4.4 Materials

Data were collected through two anonymously administered questionnaires, one for parents and one for education providers. The questionnaires were designed specifically for this study. Findings from the two previous qualitative studies described in Chapters 4 and 5 that have investigated the views of parents, young people, and education providers were used in the design of the questionnaires.

In Chapter 4, mothers and young people identified a number of ASD related life skill challenges (e.g. daily living skills; social skills; peer-relationships; self-management) and described their aspirations in relation to work, education, independent living and romantic relationships. They expressed the need for individualization of life skills support and identified areas that they believed that the support should target (e.g. social skills; daily living skills; self-management). They showed a preference for mentoring/befriending while they also discussed other forms of support (e.g. group work; online platform). Mothers talked about their preferred role and involvement in the support delivered to the young people and described their difficulties in identifying and accessing life skills support.

In Chapter 5, education providers described the life skill challenges experienced by their pupils (e.g. daily living skills; social skills) and aspects of adulthood transition. They discussed the areas that they target with the support (e.g. daily living skills; sexual relationships), ways they work with their pupils (e.g. group work; support incorporated into the curriculum), resources that they use (e.g. links with the community; participation in activities) and their abilities and skills to support their pupils.

The above findings provided the basis for the design of the two questionnaires. The aim of the questionnaires was to convert these findings into quantitative data that would allow the research hypotheses to be tested. Questionnaires were developed following recommendations from Blair, Czaja, and Blair (2014). The aim was to design questions that were relevant to the research aims while also being relevant, interesting and easy to answer for the participants.

Four sections were common in both questionnaires: Personal information; Perceived challenges; Offered training and support; Desired training and support. An additional section, called Demographics, was only included in the questionnaire designed for parents. Its aim was to collect information on ethnic background, income and educational level of participants. The questionnaires included Likert-type, multiple choice, ranking, yes/no and open questions.

It was important to create a logical relationship between questionnaire items and sections, beginning with relatively easy questions and moving progressively into more demanding ones. The initial questions of the Personal information section aimed to establish that the participants belonged to the target population and to obtain some background information. These were followed by questions in the Perceived challenges section requesting from participants to evaluate the life skills challenges experienced by their pupils or children.

These questions regarding life skills challenges were judged to be particularly relevant to the participants, while also required them to tap into an easily accessible area of experience and knowledge. In the next section, “Offered training and support”, participants were asked to evaluate their satisfaction with life skills provision at schools. The items in this section were almost identical to the life skills challenges that participants had been asked to evaluate in the previous section. Therefore, after thinking about life skills challenges they were asked to consider how well these were targeted by the schools. Education providers were also asked to rate how confident they felt in providing support around these challenges and how useful they found a number of resources.

In the next section, “Desired training and support”, participants were asked to identify their desired life skills training and support. In the two previous sections they had already evaluated life skills challenges of their pupils and children and life skills provision at schools. Therefore, thinking about what types of support they would like to access or provide was thought to be the natural conclusion. The final section in the parental questionnaire, “Demographics”, asked participants to provide some sensitive information such as annual income and educational level, although, a *‘do not wish to answer’* option was available. Despite the fact that the questionnaires were designed to capture a lot of information they required approximately 15 minutes to complete, minimizing participant burden. Input in the design of the questionnaires was also received from the supervisory team.

Items in the Likert-type, multiple choice, and ranking questions were echoing life skill challenges; desired outcomes in adulthood; desired training and support; resources that education providers use to support their pupils; areas that schools target with their support that the participants had identified in Chapters 4 and 5. Items in the Likert-type questions corresponded to the dependent variables which were used to test the hypotheses. School type was the independent variable that was used to test the hypotheses.

The Personal information section required from education providers to indicate their gender, role (multiple choice with an additional open response option) and type of school they worked (multiple choice with an additional open response option). In the same section parents were asked to indicate their gender, type of school that their child/ren attended (multiple choice with an additional open response option).

The questions included in the Perceived challenges and Desired training and support sections were identical between the two questionnaires designed for parents and education providers. Questions asked participants to rate the severity of various life skills challenges (e.g. communication; daily living skills; self-management; romantic relationships; social skills; peer relationships) experienced by their children or pupils using a five-point scale between 1 for "*not significant at all*" and 5 for "*very significant*". Also, they were asked to rate their optimism about outcomes in adulthood (independent living; relationships; education; employment) using a five-point scale between 1 for "*not optimistic at all*" and 5 for "*very optimistic*".

Participants were asked to rank their most desirable forms of life skills support (e.g. mentoring/ befriending; group work) in order of preference using a three-point scale between 1 for what they consider "*most desirable'* and 3 for what they consider "*less desirable*". They were also asked to rank the areas that they believe support should target (e.g. social and communication skills; self-management; preparation for post- secondary education) in order of preference using a 9-point scale between 1 for what they consider "*less important*" and 9 for what they consider "*most important*". Finally, they were asked to indicate their desired level of parental involvement in the support using a 10-point scale between 1 for "*not at all involved*" and 10 for "*very involved*".

All the items in the Likert-type and ranking questions included in these two sections were based on the responses of the participants, described in Chapters 4 and 5. Likert-type questions also included a 6th "*no opinion*" option. The aim was to assist those participants who felt that they couldn't express an opinion on certain life skills challenges or expected outcomes in adulthood.

The Offered training and support section included a number of identical questions between the questionnaires designed for education providers and parents. All participants were asked to rate their satisfaction with life skills provision offered by schools in various area (e.g. daily living skills; self-management; social-communication skills) using a five-point scale between 1 for "*not at all satisfied*" and 5 for "*very satisfied*". Participants were also asked to rate their level of agreement with a number of statements regarding support offered in schools (e.g. our educational establishment adequately prepares pupils for post-secondary education; our educational establishment adequately prepares pupils with ASDs for independent living) using a five-point scale between 1 for "*strongly disagree*" and 5 for "*strongly agree*".

In addition to these common questions, this section included questions designed exclusively for parents or education providers that differed between the two questionnaires. Education providers were asked to:

- Rate their confidence in assisting their pupils with various life skills (e.g. daily living skills; self-management) using a five-point scale between 1 for "*not at all confident*" and 5 for "*very confident*".
- Rate resources they use (e.g. links with the local community; resources developed within school) using a five-point scale between 1 for "*not at all useful*" and 5 "*very useful*". The questions also included a 6th *"no opinion*" option. The aim was to assist those participants who felt that they couldn't express an opinion on certain resources.
- Indicate whether they needed additional support (yes/no) and describe the types of support that they would consider useful.

Parents were asked to:

- Rate how easy it was for them to identify support around life skills for their children using a five-point scale between 1 for "*not at all easy*" and 5 for "*very easy*".
- Indicate whether they have received support from any services other than their school (yes/no) and describe the service and the support they had received and how they identified the support (multiple choice).

In the parental questionnaires, participants who had more than one child who met the study inclusion criteria were able to provide information separately for each one of them in the sections, Background information, Perceived challenges and Offered training and support. However, they did not have the same option in the Desired training and support section in order to minimize participant burden. Information around life skills challenges, outcomes in adulthood and life skills provision in schools were those that would be used to test the research hypotheses, so they had to be provided separately for each young person along with the type of school that they attended.

Two versions of the questionnaires were created: one electronic using the platform of Bristol Online Survey and one paper version. Due to time constraints it was not possible to pilot-test the questionnaires. However, a Social Validity Form (Appendix D_{11}) was included as part of the questionnaires, giving participants the opportunity to express their views on the aims, content and appearance of the questionnaires.

6.4.5 Participants

Four out of ten schools agreed to distribute the questionnaires to their parents and members of staff. Two of the schools opted to use paper questionnaires for their members of staff and electronic for the parents of their pupils. The two remaining schools opted for electronic versions exclusively. Three of the schools were based in Kent and one in London.

Seven organizations and three support groups agreed to participate. Six organizations and three support groups were in the southeast of England and one organization was in the north. Five organizations and three support groups e-mailed the questionnaire to their members, one organization advertised it on their website and one included the link in their newsletter.

In total, 124 completed questionnaires from both groups of participants were returned. For analysis purposes, some items in the questionnaires were regrouped and reduced. In parents' questionnaire, the options regarding the young person's school were regrouped and the new subcategories were:

- Mainstream school (Mainstream; Grammar School; Independent Mainstream).
- Specialist School (Mainstream School with a unit; Specialist School; Independent Specialist School).
- Further Education College.

In education providers' questionnaire, the participant's role and type of school were regrouped and reduced. The new subcategories were:

1. Role
    1.1. Teachers (teachers and SEN teachers; Head and Assistant Head; SENCOs).
    1.2. Learning support (teaching assistants and learning mentors).
    1.3. Other Professionals (any other professional within the school e.g. speech and language therapist; occupational therapists; counsellors).
2. School
    2.1. Mainstream school (Mainstream; Grammar School; Independent Mainstream).
    2.2. Specialist School (Mainstream School with a unit; Specialist School; Independent Specialist School).
    2.3. Further Education College.

These new subcategories are used to describe the characteristics of the participants.

Parents returned 81 questionnaires. Three questionnaires were excluded from the analysis, 1 did not meet the age inclusion criteria of the young person, 1 provided inconsistent responses and 1 did not specify the type of school that the young person was attending. A total of 78 questionnaires were included in the analysis. 8 parents had more than one young person who met the inclusion criteria therefore, 78 parents provided information for 86 young people. The majority of parents were female (female *N*=67; male *N*=10; missing *N*=1). The majority of young people were male (male *N*=65; female *N*=21), were almost equally distributed in the age groups 11-12 years (*N*=20),13-14 years (*N*=25), 15-16 years (*N*=18) and 17-18 years (*N*=23) and most of them were attending mainstream schools (Mainstream *N*=51; Specialist *N*=21; Further Education College *N*=14).

More than half of the parents (*N*=56) completed the Demographics section of the questionnaire. The majority were White or White British (*N*=49), had a Bachelor's degree (*N*=18), while equal numbers held a Masters degree (*N*=10) or had graduated from some college (*N*=10), and had an annual income between 11.500-45.00 (*N*=16) and 45.000-150.000 (*N*=18).

Education providers returned 43 questionnaires. 2 questionnaires were excluded because the participants indicated that they did not work in a learning support or educational capacity, 1 was excluded because the participants did not indicate the type of school they were working. A total of 40 questionnaires were included in the analysis. The majority of the education providers were female (female *N*=30; male *N*=10), they were working in specialist schools (Specialist *N*=22; Mainstream *N*=15; Further Education College *N*=3) and they were almost equally split between the roles of teacher (*N*=13), professional (*N*=12) and those with a learning support role (*N*=15).

6.4.6 Analysis

Questionnaires were analysed using SPSS. In order to test the alternative hypotheses, Kruskal-Wallis test (for statistical significance p<.05) was used along with Mann-Whitney U test (for statistical significance p<.05) as a post-hoc test. Data were ordinal therefore non-parametric tests were considered more appropriate. Additionally, comparisons were made between parents and education providers regarding their views of life skills challenges, optimism regarding outcomes in adulthood and satisfaction with school provision. The aim was to explore whether they were any significant differences between the two groups of participants. Again, Kruskal-Wallis test (for statistical significance p<.05) was used with Mann-Whitney U test (for statistical significance p<.05) as a post hoc test.

Average ranking (w=weight of ranked question * x = response count for answer choice) was calculated for each option in ranking questions. Open questions were analysed with content analysis (Elo & Kyngas, 2008). Descriptive data from Likert-type items, categorical yes/no and multiple-choice questions are provided. No opinion responses were excluded from the analysis.

6.5 Results

Results are presented separately for parents and education providers in the subsections 6.5.1 and 6.5.2.

6.5.1 Parental questionnaire

6.5.1.1 Perceived severity of life skills challenges

Parental ratings regarding the life skills challenges of their children were on the high end of the scale. Parents perceived challenges around peer relationships, romantic relationships and self-management as more important than challenges around social skills, communication skills and daily living skills.

On the other hand, parents were optimistic about outcomes in relation to employment and progression to post-secondary education. They appeared less optimistic about romantic relationships and independent living. Table 13 and Table 14 present frequencies and medians per questionnaire item.

Table 13

Perceived severity of life skills challenges among parents

Life skills challenges	1: Not significant at all	2	3	4	5: Very significant	6: No opinion	Missing	Median
Communication skills	3	18	15	25	25	0	0	4.00
Social skills	0	9	11	33	33	0	0	4.00
Daily living skills	4	23	15	17	27	0	0	4.00
Self-management	1	6	12	21	45	1	0	5.00
Peer-relationships	1	7	20	13	45	0	0	5.00
Romantic relationships	4	6	5	8	29	34	0	5.00

Table 14

Optimism regarding outcomes in adulthood among parents

Outcomes in adulthood	1: Not optimistic at all	2	3	4	5: Very optimistic	6: No opinion	Missing	Median
Independent living	21	26	15	18	6	0	0	2.00
Relationships	17	38	13	14	3	1	0	2.00
Pots-secondary education	11	19	12	24	19	1	0	4.00
Employment	13	28	19	18	8	0	0	3.00

Hypothesis$_1$

Kruskal-Wallis test was conducted with school type as the independent variable and perceived severity of life skills challenges as the dependent variable. There were no significant differences between the parents of young people who attended different types of school regarding perceived severity of life skills challenges in: communication skills (p=.932); social skills (p=.432); romantic relationships (p=.932); daily living skills (p=.141); peer relationships (p=.496); self-management (p=.815). Therefore, Hypothesis$_1$ was rejected.

Hypothesis$_2$

Kruskal-Wallis test was conducted with school type as the independent variable and optimism regarding outcomes in adulthood as the dependent variable. There were no significant differences between parents of young people who attended different types of school regarding optimism about outcomes in: independent living (p=.596); relationships (p=.827); post-secondary education (p=.337); employment (p.335). Therefore, Hypothesis$_2$ was rejected.

6.5.1.2 Offered training and support

Parents overall did not appear very satisfied with the life skills support that their children received from their schools. The majority of the ratings were in the lower to mid-range with few responses on the higher end. However, parents appeared to be more satisfied with the ability of the schools to understand the needs of their pupils, the ability to provide support tailored to those needs, preparations they offered for employment and post-secondary education and with sex and relationships education. Table 15 presents frequencies and medians per questionnaire item.

Table 15
Parental satisfaction with school provision

Areas of support$_1$	1: Not at all satisfied$_1$/Strongly disagree$_2$	2	3	4	5: Very$_1$ satisfied/Strongly agree$_2$	Missing	Median
Communication skills$_1$	27	40	7	5	7	0	2.00
Social skills$_1$	32	35	7	6	6	0	2.00
Daily living skills$_1$	43	24	10	4	5	0	1.50
Self-management$_1$	32	32	11	6	4	1	2.00
Peer-relationships$_1$	32	28	14	7	5	0	2.00
Communication between school and parents$_1$	21	29	15	7	13	1	2.00
Ability to understand the needs of pupils$_2$	19	14	19	19	15	0	3.00
Ability to provide support tailored to individual needs$_2$	22	13	22	20	9	0	3.00
Preparation for employment$_2$	15	23	30	15	3	0	3.00
Preparation for post-secondary education$_2$	13	10	33	19	9	2	3.00
Preparation for independent living$_2$	25	17	34	5	3	2	2.50
Sex and relationships education$_2$	10	13	41	17	4	1	3.00

Hypothesis$_3$

Kruskal-Wallis test was conducted with school type as the independent variable and satisfaction with support offered in various areas as the dependent variable. Analysis revealed that there were significant differences regarding satisfaction with support offered by schools in the areas of: daily living skills (p=.005); peer- relationships (p=.001); self-management (p=.000); social skills (p=.000); communication skills (p=.000); communication with parents (p=.001); ability to understand the needs of pupils (p=.001); ability to respond to the needs of pupils (p=.000); preparation for employment (p=.016); preparation for independent living (p=.012); sex and relationships education (p=.020). The only area that did not show any significant differences was preparation for post-secondary education (p=.522).

Mann-Whitney U test was applied to explore between group differences. No significant differences were identified between mainstream schools and further education colleges and between specialist schools and further education colleges. The tests revealed that parents of young people who attended specialist schools were significantly more satisfied with the support they had received from their schools than parents of young people who attended mainstream schools regarding:

- Daily living skills (p=.002, r=-0.37)
- Peer-relationships (p=.000, r=-0.42)
- Self-management (p=.000, r=-0.49)
- Social skills (p=.000, r=-0.53)
- Communication skills (p=.000, r=-0.48)
- Communication with parents (p=.000, r=-0.42)
- Ability to understand the needs of pupils (p=.000, r=-0.44)
- Ability to tailor the support to individual needs (p=.000, r=-0.54)
- Preparation for independent living (p=.004, r=-0.32)
- Preparation for employment (p=.006, r=-0.32)
- Sex and relationships education (p=.009, r=-0.30)

Parents of young people who attended specialist schools were also more satisfied with the support they had received from their school than parents of young people who attended further education colleges regarding:

- Peer-relationships (p=.009, r=-0.44)
- Self-management (p=.021, r=-0.36)
- Social skills (p=.000, r=-0.59)
- Communications skills (p=0.10; r=-0.59)
- Communication with parents (p=.013, r=-0.41)
- Ability to tailor the support to individual needs (p=.005, r=-0.47)
- Sex and relationships education (p=.019, r=-0.40)

Therefore, Hypothesis_3 was fully accepted.

6.5.1.3 Accessing life skills support

The majority of the parents reported that identifying and accessing life skills support was "*not at all easy*" or "*not very easy*" (*N*=66) and they had not received support from an external service (*N*=62). Those who had received support (*N*=16) mentioned the following services: CAMHS; Occupational Therapy; Speech and Language Therapy; Adult Support Worker; Family Support Worker; Youth clubs; Private Paediatrician; Autism charities; Short breaks. The parents who had received support from an external service managed to achieve that based on their own efforts or via the involvement of a school.

6.5.1.4 Desired training and support

More than half of the parents (*N*=48) completed the ranking questions and the question regarding their preferred level of involvement in the support. Parents prioritized their preferred areas of support in the following order (highest to lowest): 1) Social-communication skills; 2) Daily living skills; 3) Self-management; 4) Peer-relationships; 5) Romantic relationships; 6) Preparation for post-secondary education; 7) Careers advice; 8) Preparation for work placements; 9) Support with the process of university applications.

Regarding their preferred form of support parents chose the following options in the following order (highest to lowest): 1) Mentoring/Befriending; 2) Combination of one to one and group work;3) One to one support.

Parents were equally split with regards to their preferred level of involvement in life skills support. Around half of them (*N*=23) favoured a lower involvement giving an 1-5 rating, in a scale of 1 to 10 with 10 being "*very involved*", and half *(N*=25) favoured a higher involvement, giving a 6-10 rating, although higher involvement was favoured by a sight majority.

6.5.1.5 Social validity

The majority of parents (*N*=56) completed the feedback form. Results showed that, overall, parents understood the aims of the questionnaire, they found it easy to complete and believed that it covered all the relevant issues. Some of the parents mentioned additional issues that should had been addressed in the questionnaire. These included financial and legal aspects; specific mention of CAMHS; anxiety management; self- esteem issues and parent training. Table 16 presents the most popular responses per questionnaire item.

Table 16
Social Validity Results: Parental questionnaires

Questions	Most popular response	n
I understood what the questionnaire was about	Agree/Strongly agree	55
The questionnaire took me a manageable amount of time to complete	Agree/Strongly agree	51
The instructions for answering the questions were clear and easy to understand	Agree/Strongly agree	47
The questions were clear and easy to understand	Agree/Strongly agree	46
The scales used to answer the questions were clear and easy to understand	Agree/Strongly agree	26
Do you think there were other relevant issues that were not covered?	No	25
Were there any questions that you found hard to answer because the options you were given to choose from did not cover your opinion or how you felt?	No	28

6.5.2 Education Providers

6.5.2.1 Perceived severity of life skills challenges

Education providers rated all the life skills challenges of their pupils quite high, with difficulties around self-management acquiring the highest ratings and difficulties around daily living skills acquiring the lowest ratings. They were also optimistic about outcomes in adulthood, reporting higher optimism for outcomes in independent living and post-secondary education rather than employment and relationships. Table 17 and Table 18 present frequencies and medians per questionnaire item.

Table 17
Perceived severity of life skills challenges among education providers

Life skills challenges	1: Not significant at all	2	3	4	5:Very significant	6: No opinion	Missing	Median
Communication skills	0	6	7	12	15	0	0	4.00
Social skills	1	2	4	13	20	0	0	4.50
Daily living skills	3	6	11	13	7	0	0	3.50
Self-management	1	4	1	13	21	0	0	5.00
Peer-relationships	0	6	3	13	17	0	1	4.00
Romantic relationships	2	4	6	13	11	4	0	4.00

Table 18
Optimism regarding outcomes in adulthood among education providers

Outcomes in adulthood	1: Not optimistic at all	2	3	4	5: Very significant	6: No opinion	Missing	Median
Independent living	1	8	8	19	3	1	0	4.00
Relationships	4	6	10	17	3	0	0	3.00
Post-secondary education	1	2	13	12	12	0	0	4.00
Employment	3	6	14	13	4	0	0	3.00

Hypothesis$_4$

Kruskal-Wallis test was conducted with school type as the independent variable and perceived severity life skills challenges as the dependent variable. There were significant differences between education providers working in different types of school regarding perceived severity of challenges in self-management (p=.042) and romantic relationships (p=.043). Significant differences were not identified in: social skills (p=.304); communication skills (p=.053); daily living skills (p=.056); peer-relationships (p=.081).

Mann-Whitney U test was applied to explore between group differences. No significant differences were identified between specialist schools and mainstream schools and between mainstream schools and further education colleges. Tests revealed that education providers in specialist schools rated significantly higher than education providers in further education colleges difficulties in:

- Romantic relationships (p=.031, r=-0.43)
- Self-management (p=.006, r=-0.35)

Therefore, Hypothesis$_4$ was partially accepted.

Hypothesis$_5$

Kruskal-Wallis was conducted with school type as the independent variable and optimism regarding outcomes in adulthood as the dependent variable. Results revealed that there were no significant differences in optimism regarding outcomes in: independent living (p=.639); relationships (p=.273); post-secondary education (p=.229); employment (p=.123). Therefore, Hypothesis$_5$ was rejected.

6.5.2.2 Offered training and support

Education providers were overall satisfied with the support offered by their school. They rated higher the ability of their school to understand the needs of pupils and the ability to provide support tailored to those needs. Also, they gave high ratings to the support offered around communication and social skills, self-management and the communication with parents. Education providers rated lower the support around daily living skills, peer relationships and preparation for independent living. Table 19 presents frequencies and medians per questionnaire item.

Table 19
Education providers' satisfaction with school provision

Areas of support	1: Not at all satisfied$_1$/Strongly disagree$_2$	2	3	4	5: Very satisfied$_1$/Strongly agree$_2$	Missing	Median
Communication skills$_1$	0	4	12	16	8	0	4.00
Social skills$_1$	1	4	7	13	8	7	4.00
Daily living skills$_1$	2	9	11	12	6	0	3.00
Self-management$_1$	0	6	12	18	4	0	4.00
Peer-relationships$_1$	0	9	14	13	4	0	3.00
Communication with parents$_1$	0	0	5	21	13	1	4.00
Ability to understand the needs of pupils$_2$	0	1	1	16	22	0	5.00
Ability to provide support tailored to individual needs$_2$	1	1	0	16	22	0	5.00
Preparation for employment$_2$	1	1	8	23	7	0	4.00
Preparation for post-secondary education$_2$	1	1	4	20	13	1	4.00
Preparation for independent living$_2$	1	6	13	18	2	0	3.50
Sex and relationships education$_2$	2	2	8	25	3	0	4.00

Hypothesis$_6$:

Kruskal-Wallis test was conducted with school type as the independent variable and satisfaction with life skills support in various areas as the dependent variable. There were significant differences regarding satisfaction with school provision between education providers working in different types of schools in the areas of: daily living skills (p=.006); social skills (p=.004); preparation for employment (p=.048). No significant differences were identified in the areas of: peer-relationships (p=.066); self-management (p=.387); communication skills (p=.461); communication with parents (p=.425); ability to understand the needs of pupils (p=.267); ability to provide support tailored to individual needs (p=.460); preparation for post-secondary education (p=.111); preparation for independent living (p=.127); sex and relationships education (p=.372).

A Mann-Whitney U test was applied to explore between group differences. No significant differences were identified between specialist schools and further education colleges and between mainstream schools and further education colleges. Tests revealed that education providers in specialist schools were significantly more satisfied than education providers in mainstream schools with the support that their school provides around:

- Daily living skills (p=.001, r=-0.54)
- Social skills (p=.002, r=-0.42)
- Preparation for employment (p=.010, r=-0.42)

Therefore, Hypothesis$_6$ was partially accepted.

6.5.2.3 Perceived confidence

Education providers were confident in their abilities. They rated higher their abilities to support their pupils with social-communication skills, peer-relationships, self-management, understand their specific needs and to provide tailor-made support. Table 20 presents frequencies and medians per questionnaire item.

Table 20

Perceived confidence among education providers

Areas of support	1: Not confident at all	2	3	4	5: Very confident	Missing	Median
Daily living skills	0	8	14	12	6	0	3.00
Social-communication skills	0	4	9	17	9	1	4.00
Peer-relationships	0	5	14	15	6	0	4.00
Self-management	0	5	14	14	6	1	4.00
Romantic-relationships	3	14	6	11	4	2	3.00
Understand specific needs of pupils	2	2	9	10	17	0	4.00
Respond to individual needs of pupils	0	3	7	13	17	0	4.00

Hypothesis$_7$

Kruskal-Wallis test was conducted with school type as independent variable and perceived confidence as the dependent variable. There were significant differences between education providers working in different types of schools regarding their confidence when supporting their pupils with: romantic relationships (p=.023); peer-relationships (p=.011); social-communication skills (p=. 023). No significant differences were identified in the areas of: self-management (p=.165); daily living skills (p=.191); ability to understand the needs of pupils (p=.113); ability to provide support tailored to individual needs (p=.176).

A Mann-Whitney U test was applied to explore between group differences. No significant differences were identified between specialist schools and further education colleges and between mainstream schools and further education colleges. Tests revealed that education providers in specialist schools were significantly more confident than education providers in mainstream schools in supporting their pupils with:

- Peer-relationships (p=.004, r=-0.47)
- Social skills (p=.011, r=-0.43)
- Romantic relationships (p=.009, r=-0.41)

Therefore, Hypothesis$_7$ was accepted.

6.5.2.4 Resources used

Education providers rated all the resources quite high although, there was also a high number of no opinion responses. Links with the local community and after school clubs and activities acquired higher ratings. Among the external services and resources that they use participants identified: CAMHS; ASDAN; NHS; Counselling. Among the resources developed within the school participants included: functional skills activities; physical, social and health training packages; Kagan strategies, PSHE workshop.

Participants also mentioned a number of activities that they take part with their pupils such as rock climbing, sports training and travel training. Finally, schools had developed links with a local college and a church which were part of their local community. Table 21 presents frequencies and medians per questionnaire item.

Table 21
Perceived usefulness of resources among education providers

Resources	1: Not useful at all	2	3	4	5: Very useful	6: No opinion	Missing	Median
Own skills and expertise	0	11	0	8	19	3	0	4.50
External services or resources	2	4	7	5	7	16	0	4.00
Resources developed within school	0	0	8	10	12	11	0	4.00
Taking part in external activities	0	0	8	11	9	13	0	4.00
Links with the local community	0	3	6	5	8	19	0	5.00
After school clubs and activities available at school	1	1	7	7	15	10	0	5.00

Hypothesis$_8$

Kruskal-Wallis test was conducted with school type as independent variable and perceived usefulness of resources used as the dependent variable. There were significant differences between education providers working in different types of school regarding the perceived usefulness of: external services and resources (p=.041); resources developed within school (p=.031); participation in external activities (p=.031); after school clubs and activities (p=.045). There were no significant differences in own skills and expertise (p=.081) and links with the local community (p=.151).

Mann-Whitney U test was applied to explore between group differences. No significant differences were identified between specialist schools and further education colleges and between mainstream schools and further education colleges. Test revealed that education providers in specialist schools rated higher than education providers in mainstream schools the usefulness of:

- External services and resources (p=.030, r=.0-44)
- Resources developed within schools (p=.023, r=-.42)
- Taking part in external activities (p=.004, r=-.55)
- After school clubs and activities (p=.016, r=-.44)

Therefore, Hypothesis$_8$ was accepted.

6.5.2.5 Desired training and support

The majority of the education providers (*N*=21) did not indicate that they need further training. However, a strong minority (*N*=17) believed that additional training would be beneficial. Among the areas they specified were training that would enable them to help their pupils with mental health, relationships, communication skills, social skills, independent living and training that would help them to assist their pupils in understanding their needs and their diagnosis. Education providers also expressed the need to learn more about available resources and training programs, particularly those developed for pupils with high functioning ASDs.

Education providers favoured a high involvement of parents in the training with the majority (*N*=29) giving a 7-10 rating, in a scale of 1 to 10 with 10 being “very involved”. Most of the education providers (*N*=28) completed the ranking questions. They prioritized areas of support in the following order (highest to lowest) :1) Social-communication skills; 2) Daily-living skills; 3) Self-management; 4) Peer-relationships; 5) Preparation for post-secondary education; 6) Preparation for work placements; 7) Career advice; 8) Romantic relationships; 9) Support with university applications.

Regarding their preferred form of support participants chose the following options in the following order (highest to lowest): 1) Combination of one to one support and group work ;2) Training delivered as part of the school curriculum; 3) Mentoring/Befriending.

6.5.2.6 Social validity

The majority of the participants (*N*=34) completed the Feedback Form. Results showed that, overall, they understood the aims of the questionnaire, they found it easy to complete and believed that it covered all the relevant issues. Participants mentioned additional issues that they would have liked to be included in the questionnaire such as co-presentation of OCD and anxiety in girls and issues around self-care.

A high number of participants (*N*=8) reported that they struggled to generalize as the needs of their pupils can vary. This could potentially influence the support they would consider appropriate in each case. They suggested that offering them the option to provide information about their pupils’ age would have been useful.

> *‘Specify age of student-if completing this considering a year 7 you would have very different views than a year 12”*
>
> *(SENCO-Grammar School)*

"It is difficult to answer generally at times as each of our children are very different and benefit from adapting programs and approach to cater for their needs"

(Play therapist-Specialist School)

The number of education providers who indicated that they understood the overall aims of the questionnaire was lower (*N*=24/68%) compared to that of the parents (*N*=55/98%). A high number of education providers mentioned that they struggled to answer the questions regarding the needs of their pupils and therefore comment on the support they consider necessary. This perceived difficulty may have confused them as to the purpose of the questionnaire since they couldn't provide the answers that they considered relevant and appropriate. Table 22 presents most popular response per questionnaire item.

Table 22:

Social Validity Results: Education provider's questionnaires

Questions	Most popular response	n
I understood what the questionnaire was about	Agree/Strongly agree	24
The questionnaire took me a manageable amount of time to complete	Agree/Strongly agree	28
The instructions for answering the questions were clear and easy to understand	Agree/Strongly agree	23
The questions were clear and easy to understand	Agree/Strongly agree	23
The scales used to answer the questions were clear and easy to understand	Agree/Strongly agree	23
Do you think there were other relevant issues that were not covered?	No	28
Were there any questions that you found hard to answer because the options you were given to choose from did not cover your opinion or how you felt?	No	20

6.5.3 Comparisons between parents and education providers

Kruskal-Wallis test was conducted with participant type as independent variable and perceived severity of life skills challenges as dependent variable. There were no significant differences between parents and education providers regarding perceived severity of challenges in: daily living skills (*p*=.767); communication skills (p=.2); peer-relationships (p=.696); self-management (p=.882); social skills (p=.236) and romantic relationships (p=.127).

Kruskal-Wallis test was conducted with participant type as the independent variable and optimism regarding outcomes in adulthood as dependent variable. Education providers were more optimistic about outcomes in independent living (p=.000, r=-0.31); relationships (p=.000, r=-0.32) and employment (p=.034, r=-0.18) and no differences were identified in post-secondary education (p=.085).

Kruskal-Wallis test (100% of Shapiro-Wilk values <.05) was conducted with participant type as independent variable and satisfaction with support as dependent variable. Education providers were significantly more satisfied in all areas of life skills provision than parents:

- Daily living skills (p=.000, r=-0.51)
- Peer relationships (p=.000, r=-0.46)
- Self-management (p=.000, r=-0.56)
- Communication skills (p=.000, r=-0.57)
- Social skills (p=.000, r=-0.53)
- Communication with parents (p=.000, r=-0.53)
- Ability to understanding the needs of pupils (p=.000, r=-0.50)
- Ability to respond to needs of pupils (p=.000, r=-0.56)
- Preparation for employment (p=.000, r=-0.51)
- Preparation for independent living (p=.000, r=-0.43)
- Preparation for post-secondary education (p=.000, r=-0.45)
- Sex and relationships education (p=.000, r=-0.37)

6.6 Discussion

The aim of this cross-sectional study was to investigate and compare the views and experiences of parents whose children attend different types of school and education providers who work in similar establishments. Results revealed some similarities between the groups of participants, despite the presence of prominent differences.

Parents rated the life skills challenges of their children quite high. Further analysis did not reveal significant differences between those parents whose children attended different types of school. This could suggest that young people with high functioning ASDs who attend mainstream, specialist schools and further education colleges may actually have similar needs, at least when it comes to life skills. Regarding expected outcomes in adulthood further analysis did not reveal significant differences between parents whose children attended different types of school.

Both these findings could indicate that parental aspirations and necessity of support around life skills may not differ between young people who attend specialist schools, mainstream schools and further education colleges. More to that, they could contradict previous studies which suggest that it is the parents of pupils who attend specialist schools those who prioritize social aspects of support and who also have lower expectations (Casey et al., 2006; Parsons et al., 2009_b).

Parents overall were not very satisfied with the support their children had received from their schools. Analysis revealed that parents of young people who attended specialist schools were significantly more satisfied than parents of young people who attended mainstream schools and further education colleges. However, it can be argued that, considering the low ratings in many areas of life skills provision, results do not indicate greater satisfaction.

On the contrary, parents were less dissatisfied with specialist schools than mainstream schools and further education colleges. These findings, to some extent, contradict previous studies that showed that parents were more satisfied with the support their children had received from specialist schools (Barnard et al., 2000; Renty & Roeyers, 2005; Whitaker, 2007). It could be argued that parental satisfaction is reduced even for specialist schools when all other aspects of school provision are removed, and life skills provision is the only focus.

Preparation for post-secondary education was the only area of life skills provision that did not reveal significant differences in satisfaction between parents whose children attended different types of school. More to that, both parents and education providers were significantly more optimistic about outcomes in post-secondary education compared to outcomes in employment, relationships and independent living.

In the UK there is an expectation for young people to stay in education or training until the age of 18 and for young people with an EHC plan potentially until the age of 25 (DfE,2015). It is possible that these requirements may have placed additional pressures upon different types of school to prepare their pupils with ASDs for post-secondary education. These preparations could have increased satisfaction and therefore, optimism among parents and education providers.

Education providers were significantly more optimistic than parents regarding outcomes in independent living, post-secondary education and employment. It could be argued that their role in preparing their pupils for adulthood may have influenced their perceptions. If they aim to teach their pupils the skills that will enable them to lead successful adult lives, they must believe that successful outcomes are within the reach of their pupils.

Education providers rated their pupils’ life skills challenges quite high. Further analysis revealed that education providers in specialist schools rated challenges around romantic relationships and self-management significantly higher than education providers in further education colleges. The finding regarding romantic relationships is somewhat surprising when taking into consideration the age group of the pupils, 16-18 years, who attend further education colleges. It could be assumed that concerns around relationships may be more prominent among the young people in late adolescence. Furthermore, difficulties around self-management such as anxiety or depression may not be immediately obvious. Little knowledge around the needs of pupils with ASDs may make it difficult for these to get noticed.

A previous study has shown that further education colleges may struggle to meet the needs of pupils with ASDs (Barnard et al., 2000). Findings from the present study can be perceived as another proof of the of lack of specialized support offered in these establishments. Therefore, less obvious difficulties around romantic relationships and self-management, may go undetected. However, it should also not be ruled out these difficulties are not prominent among pupils with ASDs who attend further education colleges.

Education providers were overall satisfied with their provision, rating all aspects quite high. Those working in specialist schools expressed higher levels of satisfaction with the support offered by their school around social and communication skills, daily living skills and preparation for employment than those working in mainstream schools. Recent research findings from a US based study showed that pupils with ASDs but without intellectual disability were less likely to receive daily living skills training at school than those with intellectual disability (Chiang & Lee, 2017). According to the same study, the special education classroom was the most common setting for receiving daily living skills training. It appears that, from the perspective of education providers, support around social and communication skills and preparation for employment can also be among the areas that specialist schools have better provisions than mainstream schools.

Overall, fewer significant differences regarding satisfaction with life skills support were identified between specialist schools and further education colleges in both parental and education providers' questionnaires. This finding could indicate greater satisfaction with life skills support in further education colleges than mainstream schools. Absence of sufficient literature regarding support offered in further education colleges makes it difficult to interpret this finding. It may serve as another indication that further education colleges are not in a position to identify and prioritize life skills challenges among their pupils with ASDs. Therefore, members of their staff may be satisfied with the level of support they offer although, in reality, it may be inadequate. It could also however, mean that further education colleges have better provisions than mainstream schools and this is reflected in education providers' and parents' views.

Education providers were overall confident in their abilities to support their pupils. However, given that this finding contradicts an expressed need by a significant number of participants for additional training it should be interpreted with caution. Education providers in specialist schools were more confident in supporting their pupils with peer-relationships, social communication skills and romantic relationships than education providers in mainstream schools. It is possible that widely documented peer difficulties experienced by pupils in mainstream environments including bullying and peer rejection (Barnard et al., 2000; Humphrey & Symes, 2010; Rowley et al., 2012; Wainscot et al., 2008) may have influenced how participants perceived their professional efficacy.

Education providers rated all the resources quite high. Education providers in specialist schools rated external services, resources developed within the schools, after school clubs and activities and taking part in external activities, higher than education providers in mainstream schools. This could indicate that specialist schools make better use of more resources than mainstream schools. However, the high number of *“no opinion*” responses in almost every item in this section is revealing. It could suggest that overall, the use of various resources with the exception of expertise among the staff is low in both types of schools.

Results from parents and education providers regarding areas of priority around life skills support and preferred types of support have strong similarities. Both groups ranked support around social and communication skills as first among their priorities. Support around daily living skills and self-management were also high among their preferences. Education providers rated support around romantic relationships lower than parents. This finding is quite surprising.

Research has shown that young people with high functioning ASDs display more inappropriate sexual behaviour than their neurotypical peers (Wainscot et al., 2005). Previous studies have reported reluctance on behalf of the parents to discuss sexuality with their children (Ballan, 2012). Parents often question their child’s ability to understand the topic, believe that the topic may not be relevant for their child or that discussion can lead to fixation on the topic (Ballan, 2012). In this present study there was a high number of “*no opinion*” responses when parents were asked to rate the severity of their children’s’ difficulties with romantic relationships. It is possible that education providers are also finding it challenging to support their pupils with romantic relationships. Given the well documented struggle of the parents to approach this subject with their children, there is a danger that no one is responding to this need adequately.

Both parents and education providers rated the need for support around communication-social skills; self-management; peer-relationships; daily living skills higher than more specific preparations for adulthood transition such as preparation for post-secondary education, work placement; and advice with careers and university applications. This finding could signal there is always a high level of need around life skills regardless of the age group of the pupil or the type of school.

Views of education providers regarding life skills provision contradict those of parents since they were significantly more satisfied with the support offered by their schools. However, there were no significant differences between parents and education providers regarding perceived severity of life skills challenges experienced by their children or pupils. This finding contradicts a previous study which have shown that parents tend to report more and greater impairments than teachers (Mayes & Lockridge, 2017). It appears that the main point of disagreement between parents and education providers is the support currently offered in schools.

Education providers expressed the desire for high involvement of parents in the training, therefore perceiving parental involvement as beneficial. Parents appeared to be equally split between high and low involvement in the training. It is possible that this could be one of the controversial aspects of school support. In a previous study (Dillon & Underwood, 2012) parents reported high levels of communication with schools. As a result, problems at school were being fed back home at a time when they wanted to distance themselves from schools. Belief among education providers that parents should be highly involved in the training may increase the pressure on parents when they feel they need to take a step back.

Both groups identified mentoring/befriending and combination of one to one and group work in their preferred methods of support. Parents favoured mentoring/befriending and one to one support and education providers favoured more a group format. It is likely that education providers based their responses on the support that they currently offer and given that they were satisfied with their provisions they had no desire to change them. However, parents may have based their answers on what they considered as their desired form of support regardless of whether this was offered or not.

6.7 Implications for research and practice

Parents did not appear very satisfied with the support offered by their schools around life skills. Parents of young people who attended specialist schools were among the most satisfied. However, lower ratings among most areas of life skills support were consistent. On the contrary, education providers appeared satisfied with the life skills support offered by their schools.

Parents and education providers had similar views regarding perceived severity of life skills challenges of their children and pupils and on what they considered most desirable training and support. Parents and education providers have a lot of common ground and better communication and co-operation between them may help improve current provisions, their main point of disagreement.

Parents identified mentoring/befriending as the most desirable form of support while education also prioritized one to one support and mentoring/befriending. Further research could explore the applicability of mentoring/befriending and individualized approaches as these appear to be considered beneficial by those who receive and implement interventions.

Education providers in mainstream schools struggled to assist their pupils with social-communication skills, romantic and peer relationships. Given that pupils in mainstream schools interact with their neurotypical peers on a daily basis this is a worrying finding. More support should be offered to education providers to assist their pupils with peer relationships and to help them engage with their peers.

Findings indicated fewer differences regarding satisfaction with life skills support between specialist schools and further education colleges. This finding contradicts previous findings regarding the ability of these establishments to support their pupils with ASDs. Therefore, further research is required to investigate the general support and more specifically aspects of life skills support offered to pupils with ASDs in further education colleges.

6.8 Strengths and limitations

This was the first study to investigate exclusively the views and needs of parents and education providers regarding the life skills support offered in various types of schools. Social validation forms revealed that participants overall understood the aims of the questionnaires, found them easy to complete and believed they covered all relevant areas. Parents and education providers who took part were representing mainstream, specialist schools and further education colleges, therefore offering insights into the support and training that these different educational establishments offer.

The most significant limitation was the small number of participants, although the survey was well advertised with four schools, seven organizations and three support groups acting as gatekeepers. The small sample size could have affected hypothesis testing as it increases the possibility of Type 2 errors and the rejection of the alternative hypothesis. The very strict inclusion criteria may have effected participation. No incentives were given to participants. However, offering small incentives such as a raffle ticket or a voucher worth £5 or £10 for the first 50 or 100 questionnaires may have increased the number of responses. Use of paper questionnaires may have increased the number of responses among education providers. This would have allowed the schools to better monitor the completion rates and perhaps prompt or encourage more members of their staff to complete and return their questionnaires. The researcher could have also visited the schools to distribute paper questionnaires to the education providers.

Although two schools who opted for the online version exclusively were requested to send the Invitation e-mail twice, it was not possible to monitor the uptake in each school. Three out of four schools who acted as gatekeepers took part in the second study (Refer to chapter 5). These schools had already established provisions around life skills, therefore the views expressed by their staff members may not have been entirely representative.

There was only a small number of education providers who worked in a further education college. Since these establishments constitute educational placements for young people with ASDs the results of this study cannot be considered comprehensive. Education providers reported that they struggled to answer some of the questions since they couldn’t specify the age of the pupils they work with. Including this option could potentially have helped participants provide more in-depth information. Finally, the lower response rates in ranking questions among parents and education providers is a clear indication that they found them difficult to complete. Limiting the options in each question could have increased the response rate.

6.9 Conclusion

Parents and education providers had different views regarding satisfaction with school provision however, they shared similar views regarding needs of the young people and the most appropriate training and support. Better communication between the two may actually contribute towards improving the life skills support offered. Individualized approaches including mentoring /befriending should also be more widely explored.

6.10 Rationale for next chapter

This was the third study of the thesis. Quantitative data allowed comparisons between different groups of participants and assisted in the exploration of previous qualitative findings. The next chapter brings together the main findings from the all three studies, discusses contributions to knowledge, makes suggestions for research and practice and summarizes the main strengths and limitations of the research.

Chapter 7: Conclusion

7.1 Chapter summary

The literature review provided the background of this thesis which included three phases of data collection and employed a mixed methods design. The principal findings were the following:

- Need for individualized life skills support and specific request for mentoring/befriending.
- Generic life skills support in schools cannot meet the needs of pupils with ASDs.
- Current life skills support in schools for pupils with ASDs is offered in an unstructured and informal manner.
- Schools make limited use of opportunities that will enable the generalization of learned skills.
- Request from parents and education providers to strengthen the schools' ability to provide life skills support.
- Parental conflict regarding their involvement in the support.

These findings are discussed in connection to the literature review, and to the shortcomings identified in the design of life skills interventions. Recommendations for research and practice are also presented along with the most significant strengths and limitations of the research.

7.2 Introduction

The overall aim of the thesis was to investigate the life skills provision for young people with ASDs, focusing particularly on the support and training offered in schools. The thesis had four main research aims:

a. Review and evaluate life skills interventions that are currently available for high functioning young people with ASDs.

b. Explore the views and experiences of young people with ASDs and their parents regarding life skills training and support they have received, with an emphasis on school provision, and their needs for future training
c. Investigate the views of education providers regarding the life skills training and support offered in their schools and their recommendations for improvements.
d. Identify gaps in the current provisions and suggest improvements for practice and for the design of future school-based interventions.

Life skills are considered important for independent life however, research indicates that individuals with ASDs without co-occurring intellectual disability tend to have poorer life skills than would be expected based on their cognitive abilities (Duncan & Bishop, 2015; Klin et al., 2007).

Longitudinal studies have consistently shown negative outcomes during adulthood for these individuals in the areas of independent living, employment and relationships (Howlin et al., 2004; Cederlund et al., 2008; Engstrom et al., 2003; Farley et al., 2009).

Life skills are important for adulthood. For that reason, life skills training and support should be considered as a form of preparation for adulthood. In that sense, needs and views around life skills training and support were discussed in connection to adulthood transition. Investigating the process of transition and aspects of transition planning were not among of the aims of the thesis.

A systematic literature review identified certain shortcomings in the interventions designed for high functioning young people with ASDs. Although their outcomes were promising, with improvements being reported in the various areas they tried to address, only the PEERS intervention was classified as an established EBP. MASSI, TTT, and ABA were very promising. However, these interventions require more replications from different research teams to amass adequate empirical support.

Additional issues included the limited use of social validation procedures, limited evidence regarding their applicability in a school setting and limited evidence regarding their long-term implementation potential. The literature review provided the background for the research. The latter employed a mixed methods approach consisting of three studies, two qualitative and one quantitative, connecting the aims to the methods in each phase.

In the first study (refer to Chapter 4), interviews were conducted with young people with ASDs and their mothers to explore their experiences of life skills provision and consult with them directly about the types of life skills support they would like to access. The second study (refer to Chapter 5) included focus groups with education providers, in both mainstream and specialist schools, with the aim to provide a clearer picture of the life skills training and support which take place in schools and to also identify areas for improvement.

The aim of the third study (refer to Chapter 6) was to explore and compare views and experiences among parents whose children attend different types of schools and education providers who work in similar establishments. It represented the first attempt to design an instrument for capturing and evaluating aspects of life skills provision in schools.

This final chapter brings together the main findings from all three studies, discusses contributions to knowledge, makes suggestions for research and practice, and describes the main strengths and limitations of the thesis.

7.3 Principal Findings

Need for individualized support and specific request for mentoring/befriending.

A prevailing notion, common in the three studies, was the view among young people, parents and education providers that support around life skills should be individualized. The main cause of dissatisfaction among parents and young people was that the provided support failed to take into consideration the diversity of individual circumstances of a young person with ASD. Education providers recognized the significance of tailoring the support to their pupils' needs and they considered this as an essential element of a successful approach.

Parents also expressed the need for mentoring/befriending. They identified two distinct benefits of this approach. The first one was that it can be delivered within schools, with the role of the mentor assigned to an older child or a member of staff. The second was the potential for long term implementation. Parents believed not only that this support type can continue after their children exit school provisions, but it can also be applied through various phases and transitions in their life. These can be going to university, moving out of the family home, or starting a job. Young people did not describe any specific types of support that they consider beneficial, however they expressed a strong need for support with peer-relationships. Therefore, it is possible that the parents' request for mentoring/befriending underlines the need for assistance with peer-relationships, although young people were not able to express this directly. Furthermore, in the third study (refer to Chapter 6) parents and education providers showed a preference for individualized approaches and both included mentoring/befriending among their three most favourable types of life skills support.

Generic life skills support in schools cannot meet the needs of pupils with ASDs.

Participants expressed a need for specialized life skills support since support currently available in schools cannot meet the needs of pupils with ASDs. Schools are aiming to offer life skills training to all their pupils (Gutman & Schoon, 2013) However, this generic support was not considered appropriate for high functioning pupils with ASDs as they have more specific needs.

Participants described a number of areas that they believed the support should target. These included: social-communication skills; peer-relationships; daily living skills; self-management; romantic relationships; career advice; preparation for work; preparation for post-secondary education. Parents and education providers focused extensively on the support needed around daily living skills (e.g. using public transport; maintaining personal hygiene; handing money). Participants could not make a distinction between daily living skills, which are more "practical" skills and psychosocial skills. Currently, daily living skills are not targeted in interventions designed for high functioning young people with ASDs.

However, these are essential skills that young people struggle to master and they were considered by participants as equally important as psychosocial skills. Furthermore, in Chapter 6 both parents and education providers prioritized support around life skills over more specific preparations for adulthood (e.g. preparation for work placements; preparation for post-secondary education).

They were also less satisfied with support around life skills than other aspects of school provision. Young people have significant difficulties with life skills and these seem to be a major concern among parents and education providers. As a result, there is additional pressure on schools to prioritize those in the support they offer.

Support in schools for pupils with ASDs is currently being offered in an unstructured and informal manner.

Regarding the current provision of life skills support in schools, one of the main findings was that it was offered in an informal way, with education providers structuring their approach based on three guiding principles:

- Acquiring a deep understanding of their pupils' needs.
- Building strong relationships with them.
- Engaging in a lot of casual activities.

Parents appeared confused about life skills provisions and were not always aware of the support that was available at the young person's school. It is possible that the informal nature of support had affected the level of information available to parents. Since the support was not structured but rather tailored to the needs of the pupils, it could have been difficult for education providers to offer a clear breakdown to the parents.

The education providers strongly believed that the support needs to be individualized, a belief that is aligned to the request from parents and young people. However, it has resulted in informal approaches being prioritized over evidence-based and research-based practices. In addition to the view among education providers that less structured support is more beneficial, there may be a number of other reasons that can explain why this approach is prevalent.

Studies have documented that education providers, especially in mainstream schools, have not been exposed to ASD specific approaches (Leach & Duffy, 2009; Lindsay et al., 2013) which can also include evidence-based practices in life skills support. Education providers in this study did not mention any pre-existing knowledge around ASDs, although they did not believe that this was impacting their work. However, widespread lack of knowledge could be one of the factors behind limited use of evidence-based practices.

Currently, there is an ongoing discussion and various initiatives that aim to highlight the importance of incorporating a life skills curriculum in mainstream schools for all pupils (Gutman & Schoon, 2013; House of Commons Education Committee, 2015). These are skills that could facilitate success in school and workplace such as self-control; motivation; creativity; social competence; resilience and coping; engagement in academic, social or extracurricular activities (Gutman & Schoon, 2013).

A number of initiatives have been adopted in this direction. All schools are required to teach PSHE which focuses on social, health and financial matters and aims to build confidence, resilience, self-esteem, communication, and ability to work with others (DfE, 2014$_b$) Furthermore, ASDAN (www.ASDAN.org.uk) courses offering nationally accredited qualifications around the development of personal, social, and employability skills are becoming more prevalent in schools.

Despite the widespread recognition that life skills are essential, implementation of a relevant curriculum encounters obstacles. In a relatively recent study by the Sutton Trust (Cullicane & Montacute, 2017), most of education providers believed that life skills are more important than academic qualifications to young people's success. More to that, 72% believed that their school should increase their focus on teaching life skills. However, they reported that only half of schools had a shared approach or policy on the issue, with only 17% of schools having a formalized policy. The study also identified that one of the barriers to life skills education is the focus in secondary schools on key stage 4 exam results. With schools under pressure to hit targets, which do not currently include the development of life skills, such provision is easier to be side-lined.

In this present study, education providers who worked in a mainstream school expressed the view that schools did not officially recognize the life skills support they offer as part of their role. It is likely that life skills support in mainstream schools, even for pupils with ASDs, could be neglected in favour of academic subjects. As a result, an informal and ad hoc approach to support may have been reinforced within an educational system which places priority on academic achievement.

Generalization of skills encounters serious obstacles.

Another pertinent finding refers to the obstacles in the generalization of life skills, as schools were struggling to involve neurotypical peers and parents who could help young people practice newly learned skills.

1. Engagement of neurotypical peers

Education providers were encouraging their pupils to pursue opportunities that will require them to put their learned skills into practice, such as socializing with other pupils in the school cafeteria; attend school clubs; spend lunch breaks in the mainstream school and not in the unit.

However, they were not actively facilitating this interaction within the school, so it was left up to pupils to decide whether they wished to make use of the various social opportunities during the school day. At the same time education providers recognized that, this would be a very difficult step for most of their pupils and only few of them will take that initiative on their own.

2. Communication and co-operation with parents

Findings also illustrated serious problems in the communication and co-operation between parents and schools. Parents talked about their struggle to have their views heard by schools. Education providers, although they believed that they maintained good relationships with parents, they went on to describe several instances at which parents were not always on board with the support offered by schools.

Furthermore, they rarely mentioned any occasions where they have asked or taken into consideration input from parents. Parents and education providers also hold very different views regarding satisfaction with life skills provision in schools. Education providers appeared significantly more satisfied with the support offered than parents, although both groups appeared to have similar views regarding life skills needs and prioritized the same areas of support.

Findings from Chapter 6 showed that both seemed to agree about the importance of an individualized approach to support. Parents and education providers share a lot of common ground. However, their different views regarding satisfaction with the support could again indicate that communication and co-operation between the two is not actually working as it should.

Request from parents and education providers to strengthen the ability of schools to provide life skills support.

Findings also revealed that schools are the main places where life skills support is currently offered, although this may not take place in a consistent and homogenous way across different educational settings. Parents struggled to access life skills support from external services citing a number of reasons (e.g. not knowing what support was available around life skills, and apparent fragmentation of services).

More to that, the vast majority of parents who took part in the third study (refer to Chapter 6) had not received support from any other services other than school. The expressed need from parents for mentoring/befriending also reflects a desire for support that can be delivered in schools. Furthermore, education providers had embraced that role and had taken on the responsibility of providing life skills training and support. They also appeared willing to do more in this direction with the allocation of appropriate resources (e.g. residential units within school).

Parental conflict regarding their involvement in the training.

In addition to their preference for utilizing peers or mentors, parents appeared ambivalent about their own role in the training and support designed for the young person. They expressed dissatisfaction with schools because they would not take their own advice and views under consideration when offering life skills support. When asked directly about the role they wished to have in the support designed for their children, they expressed the view that they would like to keep a separate role as parents rather than acting as a primary support person.

Results from Chapter 6 also revealed that parents were equally split regarding their level of involvement in the training. This ambivalence could in some ways reflect the limited availability of other types of support. Parents might recognize the problems from their own direct involvement, but they might not see other alternatives. Although we can assume that parents wished to be engaged in the support designed for their children, it is not possible to ignore these signs of parental conflict. These could suggest that the exact role that parents want to have in that support is not clear and cannot be taken for granted in the design of future interventions.

7.4 Consistency of findings

Most of the main findings were reflected directly or indirectly in all three studies. This indicates that young people, their parents, and education providers share similar experiences, even though their different narratives may shed light on them from a different angle. Only two main findings cannot be linked to all three studies: support in schools for pupils with ASDs is currently offered in an unstructured and informal manner and parental conflict regarding their involvement in the training.

Indications of the first were not evident in the third study. The third study in Chapter 6 explored more tangible aspects of life skill provision, such as resources used by education providers along with specific areas of support in schools. The study did not look into more basic structural elements of the support.

The second focus group study in Chapter 5 showed no direct indications regarding parental conflict. Education providers discussed their own involvement with parents, however since signs of conflict were an acutely personal experience, it was not likely for these to have been identified by an observer. The fact that these findings did not derive from all of the three studies does not minimize their significance.

This was an explorative investigation, involving different groups of participants and different methods. Therefore, even if insights from these studies share similarities cannot be identical. Table 23 presents evidence in support of the main findings in each study.

Table 23
Consistency of findings

Principal findings	Evidence		
	Chapter 4 Study 1: Interviews	Chapter 5 Study 2: Focus Groups	Chapter 6 Study 3: Cross-sectional survey
Need for individualized support and specific request for mentoring/befriending.	The need for individualization of the support was expressed by both mothers and young people and was particularly reflected in their preference for mentoring/befriending.	Education providers emphasized the importance of tailoring the support to the needs of their pupils.	Both education providers and parents identified mentoring/befriending among their three main preferences regarding their most desirable types of support.
Request from parents and education providers to strengthen the ability of schools to provide life skills support.	Parents struggled to identify and access support from external services and they identified among the benefits of mentoring/befriending the potential for school implementation.	Education providers were already supporting their pupils with life skills and were keen to take more responsibilities.	Most parents (85%) had not received life skills support from external services.
Generalization of skills Engaging neurotypical peers.	Young people struggled to engage with their peers and overwhelmingly expressed the need for assistance with peer-relationships.	Education providers did not actively facilitate any interaction with neurotypical-peers within schools or involved them in any ways in the training and support they offered.	Education providers in mainstream schools reported significant lower confidence with their skills to support their pupils with peer-relationships and romantic relationships.
Generalization of skills: Engaging parents.	Parents struggled to have their views heard by schools.	Education providers mentioned several difficulties in engaging parents with the support they offered and rarely described occasions where advice and input from parents were actively sought.	Education providers were significantly more satisfied with life skills provision in schools than parents however, both groups had similar views regarding the needs of their pupils or children respectively and prioritized the same areas of support.
Parental conflict regarding their involvement in the training.	Mothers wished to have an input in the support but also keep a separate role.	No evidence.	Parents were equally split regarding their level of involvement in the training with *N*=23 favouring a lower involvement and *N*=25 favouring a higher involvement.

Table 23 (continue)
Consistency of findings

Principal findings	Evidence		
	Chapter 4 Study 1: Interviews	Chapter 5 Study 2: Focus Groups	Chapter 6 Study 3: Cross-sectional survey
Support in schools for pupils with ASDs is currently offered in an unstructured and informal manner.	Parents were not always aware of the support available at school.	Education providers placed emphasis on understanding the specific needs of the pupils, forming strong relationships and engaging in casual activities rather than on a more structured approach.	No evidence.
Generic life skills support in schools cannot meet the needs of pupils with ASDs.	Parents and young people wanted specialized support which should target: social-communication skills; peer-relationships; daily living skills; self-management; romantic relationships; career advice.	Education providers were assisting their pupils with social-communication skills; peer relationships; daily living skills; self-management.	Both parents and education providers rated life skills challenges of young people quite high and prioritized support around social-communication skills; peer-relationships; daily living skills; self-management; romantic relationships.

7.5 Contributions to knowledge

The thesis has made several contributions to knowledge which are discussed in connection with the literature review. A review of life skills interventions, designed for high functioning young people with ASDs, revealed limited use of social validation procedures, limited evidence regarding school implementation and limited evidence regarding their potential for long term implementation.

Limited use of social validation procedures.

Less than half of life skills interventions developed for high functioning young people with ASDs have assessed consumer satisfaction and acceptability (Clarke et al., 2016; Corona et al., 2016; Curtin et al., 2015; Fullerton & Coyne, 1999; Goodman et al., 2017; Koegel et al., 2013; Lerner et al., 2011; MacKay et al,. 2007; Minihan et al.,2011; Mitchel et al., 2010; Pahnke et al., 2014; Palmen et al., 2008; Santomauro et al., 2016; Siew et al., 2017;Tse et al., 2007; Vernon et al., 2016; Webb et al., 2004; White et al., 2010;2013). None of them applied social validation procedures to inform their initial design and application.

The thesis tried to address this shortcoming by offering the opportunity to young people with ASDs and to their parents to express their views and needs for life skill training and support. This was the first study to explore the experiences of young people with high functioning ASDs and their parents of life skills provision in the UK and the first to directly consult with both groups about what kind of interventions and supports would like to be made widely available. Adoption of the insights provided from this research would be likely to increase the social validity of existing life skills interventions though, generally, the adoption of systematic social validity procedures would be even more desirable in every attempt to implement life skills interventions.

Limited evidence regarding school implementation.

Limited number of life skills interventions developed for high functioning young people with ASDs have been delivered within schools and are incorporated in the regular activities (Laugeson et al., 2014; Minihan et al., 2011; Koegel et al., 2012). Therefore, there is little research evidence on what constitutes an effective school-based intervention. Furthermore, life skills provision in UK schools is an under-investigated area and little is known about the training and support that are being delivered within schools. The thesis tried to bridge the gap between research and practice by investigating life skills training and support offered in UK schools and offering recommendations for the design of future school-based interventions.

Limited evidence regarding long-term implementation.

Very few interventions developed for high functioning young people with ASDs provided evidence that they can be implemented in different settings and continue long term (Hillier et a., 2007; Minihan et al., 2011; Koegel, et al., 2012;2013). Two of these were delivered within schools (Minihan, et al., 2011; Koegel et al., 2012), using existing resources and existing members of staff and one was implemented in a university (Koegel et al., 2013).

Investigating current practices in schools along with the needs and experiences of young people and their parents could assist in developing more sustainable interventions. These interventions will build on the existing resources and expertise. Furthermore, acceptability by education providers, parents and young people could increase their willingness to implement and receive those interventions.

7.6 Implications for research and practice

In the UK, educational establishments along with other professionals who work with SEN children and young people are expected to prepare them for adulthood. According to DfE “*Being supported towards greater independence and employability can be life- transforming for children and young people with SEN (…) All professionals working with them should share high aspirations and have a good understanding of what support is effective in enabling children and young people to achieve their ambitions*” (DfE, 2015 p9 paragraph 7.37).

These preparations should not only focus on higher education and/or employment. There is also an attention to the need to support the development of a broader range of life skills that will assist individuals to live independently, healthily, securely and enable them to participate in society. Although legislation sets out the overall responsibilities of educational establishments it does not place a strong requirement on them and there is little guidance on how to best prepare pupils with disabilities for adulthood. Therefore, education providers and researchers are those who are required to drive this process forward and to make decisions regarding the most effective practice.

The thesis makes several recommendations for improving current practices and suggestion for future investigations. What is becoming clear in the case of life skills training and support for high functioning young people with ASDs now, is that practice and research should make parallel progress in order to address current shortcomings and contribute towards to the design of more effective practices.

Introduction of relevant legislation.

Currently, legislation vaguely outlines the responsibilities of education providers who work with young people with disabilities, including those with

ASDs. However, no specific guidelines are offered on how to best support young people and what life skills training should include. Furthermore, evaluation of schools is based on academic aspects while disregarding other areas of achievement among their pupils.

The introduction of more detailed legislation that will state more clearly the responsibilities of the schools will put more pressure on them to provide support around life skills. Especially the mainstream schools, currently have few incentives to allocate resources and staff time in order to offer structured training around life skills. Outcome measures and evaluation of schools should not only focus on academic achievement and progression into post-secondary education. They should also include other aspects, such as community involvement or development of skills around independent living and employment, particularly among pupils with ASDs. This could also increase benefits for all pupils in mainstream schools as a life skills curriculum is currently overlooked in favor of more academic subjects (Cullicane & Montacute, 2017).

Assistance to education providers and recommendations regarding evidence-based practices could be more easily accessible and more clearly disseminated by relevant educational authorities, although some flexibility should also be allowed to schools. Continuous professional development regarding new advancements in the field could also be introduced, as it would increase understanding among education providers and could encourage the use of evidence-based practices.

Compared to the US the UK does not clearly specify a transition period for pupils with disabilities. Introduction of a similar clear framework with an outcomes-based approach could also provide more guidance to schools on how to prepare their pupils for adulthood.

Legislation will also need to be accompanied by the allocation of more resources. Limited resources, which is another constraint experienced by education providers who took part in this study (refer to chapter 5), is among the factors that prevents them from providing the training that they consider useful. As a result of a more concrete legislation, a clearer picture of support around life skills will start to emerge and could increase the understanding and confidence among education providers but also parents and pupils.

Findings from all the three studies highlighted the need for developing effective partnerships between parents and schools. This is something that has been considered as an essential element for the effectiveness of the support by both education providers and parents. A closer look into the participants' accounts revealed that serious obstacles exist. It became apparent that keeping an open line of communication and having regular contact with parents does not in itself guarantee an effective partnership. This is not enough to bring parents on board with the support offered by schools or improve and enhance the quality of the support offered.

An investigation by Ofsted (2011) with the aim to evaluate partnerships between mainstream/specialist schools and parents revealed that the opportunities for parents to contribute their expertise and skills were less well developed than other aspects of the schools' work with parents. Furthermore, in schools that received lower evaluation regarding their engagement with parents, the potential contribution of parents was held in low esteem. However, what this investigation also showed was that in the cases where the schools confirmed that parents had contributed or initiated ideas for improvements these ideas had been successful.

In the case of pupils with ASDs, parents can actually assist with the generalization of the learned skills. Therefore, their positive involvement and engagement with the schools, who are mainly responsible for providing life skills training and support, becomes even more crucial. While parents were well aware of the fact that schools often failed to enlist their assistance and listen to their views, education providers appeared oblivious to this possibility. Although they could describe the obstacles they encountered when parents and schools were working in different directions, they appeared to have limited understanding of some of the underlying causes or how to change this dynamic. It is worth mentioning that there may also be a number of factors that can influence this aspect of school life (organizational; financial; time constraints). Investigating, those aspects in more detail was beyond the aims of the thesis.

It appears that some initial steps can be taken to remove some of these obstacles which could be limiting the effectiveness of life skills training. Any changes will require from schools to enlist the agency of the parents, rather than maintaining communication on a surface level. The following section describes the evaluation of an event with the aim to bring together parents of young people with ASDs and professionals in order to discuss the current issues in the provision of life skills support and put forward their suggestions for improvements.

The event illustrates the relevance of the research as issues surrounding life skills support appeared to be a significant concern among parents and professionals. Attendees at the event exchanged views and ideas with each other, found the experience of interacting with parents and professionals useful and wanted to see similar events in the future to improve their knowledge around life skills training and the needs of pupils with ASDs. The event showed that even though communication and partnership can be considered as relatively easy conditions to occur, they can actually be fully utilized under the right circumstances. In this instance the event created an environment outside the constraints and demands of a school day with the only aim of fostering discussion and understanding.

Introduction of relevant legislation that would formalize aspects of life skills support could also assist to better define and enhance cooperation between parents and schools. As a result, support would be more structured and the guidelines along with the responsibilities of education providers would be more clearly outlined. This could relieve some of the existing challenges experienced between schools and parents as described in chapter 5, particularly in relation to efforts made by the schools to encourage independence among the young people. Schools and parents could focus more on improvements that need to be made rather than on dealing with day to day tasks. Parents could also start feeling more confident in the ability of the schools to support their children and as a result manage to negotiate their involvement in the support, something which they appear to be struggling with (refer to chapter 4).

In the meantime, initiatives and forums at a local level involving parents, educators and other professionals can also assist in that direction. These events could progressively evolve from creating a space for parents and professionals to communicate and exchange views and expertise to providing recommendations for practice and research.

“Supporting independence in young people with autism”
University of Kent, Medway Campus
March 2018

Representatives from local schools, services and autism organizations along with parents were invited to attend this half day event where the findings from the PhD study “*Passport to Life: Investigating the needs for life skills training among young people with autism and their parents”* were presented and discussed.

Findings based on interviews with parents and young people suggested that:

a) Schools and services may not always identify and manage the individual needs of the young people.

b) life skills training may not be offered in a consistent and homogenous way across different educational settings.

c) Parents were actively seeking to identify support around life skills however, they were not aware of what support is available and how to access it.

In order to further increase awareness and encourage discussion, representatives from local organizations, services and schools were invited to give short presentations about the life skills training they offer and answer questions from parents. The presentations were followed by an open discussion. The event aimed to highlight among professionals potential issues around the provision of support and to increase awareness among parents regarding the training offered from schools and services. Three schools, one local organization, the University of Kent student support and well-being service participated.

Funding was obtained from the University of Kent Public Engagement with Research Fund. 44 parents along with 10 professionals attended.

Evaluation involved distribution of feedback forms at the event. Two feedback forms were designed, one for parents and one for professionals. The aim of the forms was to capture attendees' views on:

- Whether the event increased their knowledge around the needs of the young people with ASD.
- Whether the event increased their knowledge regarding life skills training offered in the local area.
- Whether the event gave them the opportunity to discuss their concerns and engage with parents or professionals.

We received 35 evaluation forms (30 from parents and 5 from professionals). The format of the event was primarily short presentations while some of the schools and organizations offered additional material for attendees to pick up and take away.

The evaluation showed that the event contributed towards a better understanding of the needs of young people with ASDs; increased knowledge regarding the support offered from local schools and services; gave attendees the opportunity to discuss their concerns and engage with various professionals and parents. Attendees also requested to see more events in the future.

"Very interesting event, it has given me lots of information that I didn't know" (Parent)

"It was a really good way to reaching out to parents to offer support. Also, to gain the views of parents and for them to have a voice and feel they could put their voice across"

(Professional)

"The opportunity to talk to parents about their experiences was powerful"

(Professional)

"Additional events relating to ASD and disability and research would be great especially anxiety/mental health emotional well-being"

(Professional).

"Event on sources of support after education would be good"

(Parent)

Emphasis on the provision of individualized support while also making use of evidence-based practices.

Parents and young people expressed a need for individualization of life skills support. Education providers emphasized that tailoring the support to the specific needs of their pupils was one of the most important aspects of their work. It appears that education providers have recognized and, at least to some extent, are corresponding to this request. This can significantly contribute towards the improvement of current provisions. Unfortunately, progress on this front is also accompanied by beliefs and practices which can undo all the potential benefits of an individualized approach.

It appears that among education providers there is an overemphasis on informal and unstructured support at the expense of more structured, evidence based and possibly more effective practices. Education providers, to a lesser extent, showed lack of knowledge regarding the existence of programs and interventions designed for high functioning young people with ASDs.

However, they also justified their approach. They believed that since their pupils had very diverse and individual needs what was required from them was to understand these needs and develop strong relationships with their pupils. These two conditions were considered sufficient to enable them to provide support they deemed necessary.

It is important to break these perceived barriers regarding the use and application of research and evidence-based practices, although there are no easy and obvious solutions. Educational initiatives alone, although are necessary, they are unlikely to be efficient since it has already been documented how difficult it is for established practices to change (Boardman et al., 2005).

Furthermore, before placing the responsibility on education providers, we should acknowledge that researchers also appear to know very little about the successful application of school-based life skills interventions. Therefore, very crucial in this direction could be the design and application of life skills interventions within schools. These interventions could make use of the expertise among school staff and particularly the fact that they come in daily contact with the young people they support. Education providers have rightly pointed out that they are able to understand the specific needs of their pupils and build relationships with them.

It is not only education providers who need to increase their understanding of evidence-based practices. Researchers also need to increase their understanding of school-based practices; therefore, research and practice should progress together. One more step into that direction would be to look specifically into the application of PEERS, as this was the only identified evidence-based practice, within a UK school. So far there has been one replication of PEERS in a US school (Laugeson et al., 2014) with positive results. Collaboration between schools, researchers, parents, and young people could adapt the approach to one that might be applicable within a UK school.

Provide more hands-on support with peer-relationships and involvement of peers in the training.

Young people overwhelmingly expressed the need for support with peer-relationships. Education providers were assisting them to learn the skills that will enable them to socialize and form relationship with their peers. However, they had not taken any initiatives to facilitate interaction with neurotypical peers within schools. Findings also revealed that, at least some pupils with ASDs, could engage with various school activities.

These activities could become naturalistic and at the same time somewhat controlled environments (e.g. lower number of present pupils; focus on a specific activity; common interests among participants) where pupils with

ASDs can practice learned skills and engage with their peers. Research has shown that even a simple initiative, such as participation in lunch clubs, can significantly increase socialization among pupils with ASDs and their peers (Koegel et al., 2012).

One first step could be for these activities to be better monitored and supervised by the schools with the ultimate goal to increase interaction among pupils with ASDs and their neurotypical peers. Specific suggestions could include more social outings, trips or visits to places of interests where pupils can spend time socializing with each other, while also increasing the opportunities for collaborative work among pupils who take part in these activities.

Essential in all of these would be the involvement of pupils with ASDs in every step. Education providers will need to make sure that young people are on board with any initiatives while also monitoring the effectiveness of these initiatives (e.g. can the young person identify more friends; does he /she appear to be talking to more pupils or appear less isolated within school).

Education providers are currently working in that direction, however they use no structured approaches when it comes to generalization of life skills within the school environment. In addition to some initial steps that can be taken by schools more research is needed to look into the role that neurotypical peers can play in the life skills training. Currently very few interventions enlist the assistance of neurotypical peers (Minihan et al., 2010; White et al., 2009;2011;2013).

Education providers appeared reluctant to facilitate interactions or engage peers with the training, however researchers cannot offer more specific recommendations. Research supports that peer support could offer benefit to school children with ASD and the formalization of standardized procedures should be sought.

Explore life skills support offered in further education colleges and universities.

There is an absence of studies that have explored the support offered by further education colleges to pupils with ASDs and more specifically life skills support. Findings from this study showed that specialist schools may have provisions in local colleges in order to support their pupils. However, no further information is available as to how common this practice is. This in combination with a number of concerns voiced by education providers regarding the support offered in these establishments, makes it more imperative to acquire a better understanding of their provision around ASDs. Considering the age groups of young people who attend further education colleges, the provision of support around life skills in preparation for adulthood transition could be a hugely valuable step in that direction.

Universities can also do more to support young people with life skills by enriching their already existing provisions which are mainly focused on providing academic support. A number of universities in the UK (e.g. University of Sheffield; University of Manchester) have developed additional provisions to support their pupils with various aspects of university life. Future studies should look more closely into the support offered in universities and how these provisions can be better linked with schools to facilitate the transition to post-secondary educational settings.

Need to consult directly with the young people.

Parents and education providers appear to hold very different views regarding the life skills support that is available in schools. Parents appeared dissatisfied in contrast with education providers who appeared satisfied overall. This complicates the picture when trying to assess the effectiveness of the support and make improvements. One possible solution to this is to consult directly with the young people. Bringing the views of young people to the fore instead of relying mostly on accounts of parents and education providers may actually assist in bridging the gap between these contrasting views. It can increase our understanding of any modification that needs to take place.

Investigating the effectiveness and applicability of mentoring/befriending.

Parents expressed a need not only for an individualized approach to life skills support but specifically for mentoring/befriending. They linked this approach to certain benefits such as the potential for school implementation and long-term implementation. More focus should be placed on research regarding the applicability and effectiveness of mentoring/befriending for young people with high functioning ASDs.

The majority of life skills interventions currently offer group training with only a minority investigating the applicability and effectiveness of mentoring befriending (Curtin et al., 2015; Koegel et al., 2013; Siew et al., 2015). Mentoring/befriending (e.g. NAS) schemes currently are available however, these focus mainly on providing companionship. As a result, their effectiveness can be limited since they are not part of a more structured life skills intervention.

Further explorations are needed to understand views among parents regarding their involvement in the training.

Findings revealed signs of parental conflict and ambivalence regarding their involvement in the training and support designed for their children. These signs could be an indication that the involvement of parents may be a more complicated issue that requires more thorough investigation as a separate element of the support. Parents have a significant role to play especially when it comes to providing opportunities for the generalization of life skills.

Their exact role should not be taken for granted but should be negotiated with them as allocating any specific task may run contrary to their views and needs. In the meantime, other options such as using peers or mentors should also be more widely explored to provide more options to the young people and their families.

7.7 Strengths and limitations

The thesis included a systematic literature review and three studies, all of which had a number of strengths and limitations. These were discussed in the relevant chapters. This section outlines the overall strengths and limitation of the research.

The major strength was that it investigated the perspectives of all those involved in life skills training: young people, their parents and education providers. Their views were brought together and triangulated in order to acquire a more comprehensive understanding of the current stage of life skills training and the potential for improvements that need to be made.

Young people with ASDs were also given the opportunity to express their views regarding the training they had received and also their needs for future training. As a result, insights and recommendations are provided for involving young people with ASDs in qualitative studies.

However, all studies were observational with the aim to improve understanding of this phenomenon. Although recommendations were made for both practice and research there were no opportunities to affect current practices and bring about change or witness the possible outcomes of these recommendations.

Furthermore, sampling methods throughout the thesis presented restrictions. A considerable number of parents (all parents in the first study [refer to chapter 4] and some in the third study [refer to chapter 6]) were recruited through Autism organizations. It is expected that individuals of higher socioeconomic status are more likely to be members of these organizations (Koff, 2017). This selection process could have resulted in limited representation from different socioeconomic strata. Additionally, sample sizes in all studies were quite small. Therefore, findings cannot be considered representative, while hypothesis testing in chapter 6 may have also been affected by the small number of participants.

Additionally, all three studies were conducted in England. Wales, Scotland, Northern Ireland and England share a similar overall framework when it comes to Education and Health, while devolved nations are also responsible for setting their own policies in these areas. It is therefore possible that devolved administrations have regulated their provisions differently. Findings from the thesis refer mainly to England and more research is needed in order to explore potential differences among the devolved nations.

Furthermore, due to the exploratory nature of the thesis and investigation of various views, experiences among different groups of participants and practices literature that was relevant to many of the findings was not systematically explored (e.g. experiences of parents and educational providers on ASD related support). However, relevant literature was identified and was reported in each chapter to which findings were related.

7.8 Conclusion

The aim of the thesis was to investigate life skills provision in the UK for young people with autism spectrum disorders. The thesis utilized a mixed methods design employing both qualitative and quantitative research methods. It contributed towards the social validation of life skills interventions by consulting directly with parents and young people about the type of support they would like to be made available; improved understanding of life skills training and support that is currently available in schools and identified shortcomings in school provisions. Finally, the thesis offers recommendations for improvements in current practices and suggestion for future research.

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Search Terms

1st Search

(Autism* or ASD or Asperger* or PDD*)
AND
(Teen* or Adolescen* or Youth* or Juvenile*)
AND
(Program* or Protocol* or Train* or Guideline* or Interven*)

2nd Search

(Autism* or ASD or Asperger* or PDD*)
AND
(Teen* or Adolescen* or Youth* or Juvenile*)
AND
(Program* or Protocol* or Train* or Guideline* or Interven*)
AND
(Job* or Work* or Placement* or Vocation*)

Appendix A$_2$
Intervention ratings

Table 1

GRD Ratings on Essential and Desirable Quality Indicators

Study	Essential Quality Indicators						Desirable Quality Indicators							
	PART	IV	CC	DV	LRQ	STAT	RA	IOA	BR	FID	ATR	G/M	ES	SV
Cashin et al. (2013)	A	A	U	H	H	A	N	P	N	N	P	N	N	N
Clark et al. (2016)	H	H	A	H	H	H	N	N	N	N	P	P	N	P
Corona et al. (2016)	A	A	U	H	H	A	N	N	N	N	P	N	N	P
Curtin et al. (2015)	A	A	U	H	H	U	N	N	N	N	P	N	N	N
Dekker et al. (2015)	H	H	U	H	H	A	N	P	N	N	P	N	N	N
Fullerton & Coyne (1999)	U	H	U	A	H	U	N	N	N	N	N	N	N	N
Gantman et al. (2012)	H	H	A	H	H	A	P	P	N	P	P	N	N	N
Garcia Villamizar & Dattilo (2010)	U	A	A	H	H	A	P	P	P	N	P	N	N	N
Goodman et al. (2007)	U	H	U	H	H	A	N	N	N	N	P	N	N	N
Herbrecht et al. (2009)	H	A	U	A	H	A	N	P	N	N	P	P	N	N
Hill et al. (2017)	A	H	U	H	H	A	N	P	P	P	P	N	P	P
Hillier et al. (2007)	A	A	U	H	H	A	N	P	P	N	P	P	N	N
Hillier et al. (2011)	A	A	U	H	H	A	N	N	N	N	P	N	N	N
Laugeson et al. (2009)	A	H	A	H	H	A	P	P	N	P	P	N	N	N
Laugeson et al. (2012)	A	H	A	H	H	A	N	N	N	P	P	P	N	N
Laugeson et al. (2014)	H	H	H	H	H	A	N	N	N	P	P	N	N	P
Laugeson et al. (2015)	H	H	A	H	H	H	P	N	N	P	P	P	P	N
Lerner et al. (2011)	H	H	A	H	H	A	N	N	N	P	P	P	N	P
Lordo et al. (2017)	A	H	A	H	H	H	N	N	N	N	P	N	N	P
MacMahon et al. (2013)	U	H	U	H	H	A	N	N	N	N	P	N	N	N
McKay et al. (2007)	A	H	U	H	H	A	N	N	N	N	P	N	N	P
Minihan et al. (2011)	A	A	U	A	H	A	N	N	N	P	P	N	N	P

Table 1 (continue)

GRD Ratings on Essential and Desirable Quality Indicators

Study	Essential Quality Indicators						Desirable Quality Indicators							
	PART	IV	CC	DV	LRQ	STAT	RA	IOA	BR	FID	ATR	G/M	ES	SV
Morgan et al. (2014)	A	H	A	H	H	A	P	P	P	P	P	N	N	N
Pahnkke et al. (2014)	H	H	A	H	H	A	P	P	N	N	P	P	N	N
Santomauro et al. (2016)	H	H	A	H	H	H	P	N	N	N	P	P	N	P
Schohl et al. (2014)	H	H	A	H	H	A	P	P	N	N	P	N	N	N
Siew et al. (2017)	A	U	U	H	H	H	N	N	N	N	P	N	P	P
Spek et al. (2013)	H	H	A	H	H	A	P	P	N	N	P	N	P	N
Stichter et al. (2010)	H	A	U	H	H	A	N	N	N	N	P	N	N	N
Tse et al. (2007)	A	H	U	H	H	A	N	P	N	N	P	N	P	N
Visser et al. (2017)	H	H	H	H	H	H	P	N	P	P	P	P	N	N
Webb et al. (2004)	A	H	U	H	H	A	N	P	N	N	P	N	N	N
White et al. (2010)	H	H	U	H	H	H	N	N	N	P	P	P	N	P
White et al. (2013)	H	H	H	H	H	H	P	P	P	P	P	N	N	N
Yoo et al. (2014)	H	H	A	H	H	A	P	P	N	P	P	P	N	N

Note: PART: Participants; IV: Independent Variable; CC: Comparison Condition; DV: Dependent Variable; LRQ: Link between Research Questions and Data Analysis; STAT: Statistical Analysis; RA: Random Assignment; IOA: Interobserver Agreement; BR: Blind Raters; FID: Fidelity; ATR: Attrition; G/M: Generalization or Maintenance; ES: Effect Sizes; SV: Social Validity

Appendix A₂
Intervention ratings

Table 2

SSED Ratings on Essential and Desirable Quality Indicators

Study	Essential Quality Indicators						Secondary Quality Indicators					
	PART	DV	IV	BSLN	VIS ANAL	EXP CON	IOA	KAP	BR	FID	GM	SV
Argott et al. (2008)	A	H	H	H	H	H	P	N	N	P	P	N
Day-Watkins et al. (2014)	A	H	H	H	H	H	P	N	N	P	P	N
Koegel et al. (2012)	H	H	A	A	A	H	P	N	N	N	N	P
Koegel et al. (2013)	H	H	H	H	H	H	N	N	N	N	P	P
Mitchel et al. (2010)	A	H	H	U	U	H	P	N	P	N	P	N
Palmen et al. (2008)	H	H	H	A	A	H	P	N	N	N	P	N
Vernon et al. (2016)	H	H	A	U	U	A	P	N	N	P	N	N
White et al. (2009)	U	H	H	U	U	U	N	N	P	N	P	N

Note: PART: Participants; IV: Independent Variable; DV: Dependent Variable; BSLN: Baseline Condition; VIS ANAL: Visual Analysis; EXP CON: Experimental Control; IOA: Interobserver Agreement; KAP: Kappa; BR: Blind Raters; FID: Fidelity; G/M: Generalization or Maintenance; SV: Social Validity

Appendix B$_1$
Letter of Approval
Study 1: Interviews

medway school of pharmacy

19th April 2016

Dear Sofia

Your application for ethical approval for the project entitled *Passport to Life* has now been considered on behalf of the Medway School of Pharmacy School Research Ethics Committee (SREC). I am pleased to inform you that your study has been approved, with immediate effect.

I must remind you of the following:

1. that if you are intending to work unaccompanied with children or with vulnerable adults, you will need to apply for a DBS check; the project must be conducted under the supervision of someone who has an up-to-date DBS check; you must not be in the presence of children alone except if you have completed a DBS check;
2. that you must comply with the Data Protection Act (1998);
3. that you must comply throughout the conduct of the study with good research practice standards;
4. If you are completing this project off site, you must obtain prior approval from relevant authorities and adhere to the MSOP off site protocol.
5. to refer any amendment to the protocol to the School Research Ethics Committee (SREC) for approval.
6. You are required to complete an annual monitoring report or end of project report and submit to j.mowbray@kent.ac.uk

Yours sincerely

Dr Sarah Corlett

medway school of pharmacy

GATEKEEPER INFORMATION LETTER

The term **“gatekeeper”** is used in the study documentation to mean “Persons who are able to arbitrate access to a social field setting (young people with ASD diagnosis and their parents/legal guardians)

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism and their parents.

Lead Investigator: Sofia Chantziara
Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill

Why is this study being done?

We are doing this study because we want to investigate:

a) The needs of young people with autism along with the needs of their parents/legal guardians for a successful transition into adulthood.
b) What type(s) of life skills support they would wish to access and may consider beneficial.

What we are requesting of you as a study gatekeeper

We are requesting if your organisation would please be willing to act as a facilitator of data collection by allowing access to your members to whom study materials may be distributed? We request if you would be willing to e-mail or post Invitation Letters to parents/legal guardians who are members of your organization on the basis that the lead investigator supplies all materials and covers any costs. We also ask you to e-mail or post a reminder Invitation Letter, if needed, two months after the beginning of the study. The lead investigator will inform you whether this will be necessary or not.

After they receive the Invitation Letter parents/legal guardians who meet the inclusion criteria and express an interest in the study will be required to contact the lead investigator (contact details will be on the Invitation Letter) who will provide them with the study documents. You will not be further involved in the recruitment of participants after you sent the Invitation Letter. We only request that you may post Information Letters/Consent and Assent Forms to parents/legal guardians who will contact the lead investigator, expressing an interest in the study, but may not have access to e-mail. In this instance the lead investigator will supply all the documents and will cover any costs. We also ask to allow the lead investigator, who will adhere at all times to the policy and procedures of your organization, to be at your premises on Thursdays during coffee mornings (10:00-12:00) from 01/7/2016 to 30/11/16 and also to hold meetings with potential participants and conduct interviews at your premises.

How will data be collected?

Data will be collected from parents/legal guardians and young people through individual interviews. Interviews with young people will last 30-45 minutes and interviews with parents/legal guardians will last 60-90 minutes. Young people in the age groups 11-15 will have the additional option to conduct interviews using Skype, phone or instant messaging (Skype/e-mails).

How will participant anonymity be upheld?

We ask you to participate as a gatekeeper so that the lead investigator does not handle personal records concerning participants. The lead investigator invites the gatekeeper to participate in the study by fulfilling the role of distributing Invitation Letters to members of your organization. The lead investigator will provide all participant documents. The confidentiality of the participants remains an obligation for us before and after the interviews. We would like to inform you that: 1) Recordings of the interviews will be destroyed after they have been transcribed and analysed. 2) Personal data in paper forma, including consent forms, will be locked in a secure filling cabinet in the University for 5 years and then will be shredded 3) Transcripts of the interviews will be fully anonymized and no one will be able to identify individual participants. Interviews in the form of instant messaging will be treated as transcripts and will be fully anonymized. The lead investigator will be required to break confidentiality if a disclosure of abuse or other illegal act is being made during the interviews. In such an event the researcher will inform statutory agencies.

How will the data be used? What will happen to the results?

Findings will help the researchers better understand what young people with autism and their parents would like to see in a life skills intervention package. The results will also be presented in a PhD Thesis. They could also be reported in future publications and conference presentations. One A4 page summary of the results may be sent to national organizations, such as AUTISTICA and National Autistic Society, to inform them about the findings and the implications they may have for research and practice. The researcher will also provide copies of 2 A4 pages summary to the gatekeeper that can be distributed to members of their organization.

Do we have to take part?

No, it is up to you to decide whether or not to take part as a study gatekeeper. If you decide not to take part there will be no implications for you.

Are there any risks if I take part?

There are no risks to your taking part in this study. There is the time taken in distributing Invitation Letters to parents/legal guardians who are members of your organization and also allowing the lead investigator to use your premises, which we would fully appreciate.

Are there any benefits if I take part?

If you decide to take part we will offer you 400£ as a compensation for using your premises and for the time your staff will spent on identifying and contacting eligible participants. We also believe that the overall findings of this study could provide more understanding around the needs of young people with autism and their parents/legal guardians.

Will anyone know that I've taken part?

If you give us your permission we will list in the finalised publication that you have acted as gatekeeper in this study.

Who should I contact if I want to know more about the study?

Study Principal Investigator: Sofia Chantziara, Medway School of Pharmacy,
The University of Kent, Central Avenue, Chatham Maritime, Kent, ME4 4TB.
Tel:(01634)202920, E-mail: SC714@kent.ac.uk)

Appendix B$_3$
Gatekeeper Consent Form
Study 1: Interviews

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GATEKEEPER CONSENT FORM

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism and their parents.

Lead Investigator: Sofia Chantziara

I have read and understood the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial Here
I understand that my participation, acting as a representative of our organisation, is voluntary and that I am free to withdraw at any time, without giving a reason.	Initial Here
I understand that any personal information collected from individual interviews during the study will be anonymised and remain confidential	Initial Here
I agree, on behalf of the charitable organisation (title) ____________________to act as gatekeeper to this study. I agree to identify and distribute Invitation Letters to parents/ legal guardians who are members of our organisation on behalf of the study lead researcher, Sofia Chantziara. I also agree to allow the lead researcher to conduct interviews at our premises, be at our premises on Fridays during coffee mornings in order to meet with potential participants and hold meetings with participants at our premises on different days during the week.	Initial Here

Name of Participant (Print)

Signature Date

Name of Researcher (Print) Sofia Chantziara

Signature Date

Appendix B_4
Participant Invitation Letter
Study 1: Interviews

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Dear Sir/Madam,

We are a team of researchers in **Medway School of Pharmacy** and **we want to learn more about the skills that young people with autism need for a successful transition into adulthood.** We would like to talk to families of young people with autism and we invite parents/legal guardians and young people to take part. If your son/daughter meets the inclusion criteria then both of you can take part.

Inclusion Criteria

1. Has a diagnosis of Autism, Asperger Syndrome (AS) or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
2. At or above the age of 11
3. Below the age of 22
4. Attending or have attended a secondary educational setting that caters for pupils with no global learning disability
5. No intellectual disability
6. Good verbal ability

We are not able to provide translators therefore we can only interview participants who are fluent in English.

The study will involve individual interviews that can take place either at (Gatekeeper), Medway School of Pharmacy or your own home. As a thank you for taking the time to participate we will offer parents/legal guardians a 25£ LovetoShop Voucher and young people a 10£ AMAZON voucher. You are receiving this invitation letter from (Gatekeeper) on behalf of Medway School of Pharmacy so that the research team does not access your personal records.

If you meet the inclusion criteria and would like to learn more about the study you can contact the main researcher Sofia Chantziara (Email: SC714@Kent.ac.uk.Telephone:(01634)202920) who will provide you with the full information package.

Thank you for taking the time to read this Invitation Letter.

Kind Regards,
Sofia Chantziara

medway school of pharmacy

PARTICIPANT INFORMATION LETTER

Main Researcher: Sofia Chantziara
Email: SC714@kent.ac.uk
Telephone: (01634)202920

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism and their carers

My name is Sofia Chantziara and I am a PhD student (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill) in Medway School of Pharmacy. I want to invite you to take part in my study. Before you decide, I would like you to understand why I am doing this study and what it would involve for you. I will describe the study and go through this Information Letter. If you agree to take part, I will then ask you to sign a Consent Form.

What is the purpose of the study?

The aim of the study is to investigate the needs of young people with autism along with the needs of their parents/legal guardians for a successful transition into adulthood.

Why have I been contacted?

I want to talk to parents/legal guardians of young people with a diagnosis of autism. In order for you to participate in the study your child/ren should meet the following criteria:

1. Have a diagnosis of Autism, Asperger (AS) or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
2. At or above the age of 11
3. Below the age of 22
4. Attending a secondary educational setting that caters for pupils with no global learning disability
5. No intellectual disability
6. Have good verbal ability

Do I have to take part?

No! Participation is entirely voluntary and your decision will not affect any of the services that you and your child/ren are receiving.

What will happen to me if I take part?

If you decide to participate I will invite you to attend an individual interview. I will ask you questions regarding your views and needs for independence and also the types of life skills support you would consider beneficial and you would like to access. The interview will last 60-90 minutes and will be audio recorded.

What are the possible risks and disadvantages of taking part?

There are no major risks to taking part in this study. There is a small possibility that you may feel anxious or distressed talking about your experience with autism, your needs and the future. I will take every step necessary to minimize any feelings of discomfort during the interview.

Will the study help me?

The study will not help you directly. The collective study results may benefit young people with autism and their parents/legal guardians in the future as they will raise awareness about their needs and could help us understand what should be included in a life skills intervention package.

Who is organizing the research?

Medway School of Pharmacy is organizing and funding the research*.*

Who has reviewed the study?

The Medway School of Pharmacy Ethics Committee has reviewed and approved the study*.*

What if I have a question?

If something is not clear to you and you want to ask questions you should contact Sofia Chantziara (contact details on page 1) who will do her best to answer your questions or her supervisor Dr Alison Bratt (E-mail: amb54@kent.ac.uk.Telephone: (01634) 892 944).

What if I want to complain?

If you have a complaint you can contact Dr Sarah Corlett (E-mail: S.A.Corlett@kent.ac.uk. Telephone: (01634) 88 8909) who is the Chair of the Ethics Committee in Medway School of Pharmacy.

What will happen if I do not want to carry on with the study?

You are free to withdraw anytime, before or during the interview and no one will attempt to stop you or ask you to give any reasons for your decision.

Will my participation in the study be kept confidential?

Your confidentiality remains an obligation for us before and after the interview. We want you to know that:

- Personal data in paper format will be locked in a secure filling cabinet in the University for 5 years and then will be shredded.

- All audio recordings will be destroyed after they have been transcribed and analysed.

- In all transcripts of the individual interviews you will be referred to as "*Participant 1 carer male/female", "Participant 2 male/female"* etc and no one will be able to identify you.

- Authorised people (researchers, examiners, supervisors, regulatory authorities) could look at the data but they will not be able to identify you.

- University will keep the anonymised data for use in future studies approved by an appropriate research ethics committee.

However, if during the interview you will talk about incidents of abuse or other illegal acts then the researcher will be required to break confidentiality and inform statutory agencies.

What will happen to the results of the study?

The results will be presented in a PhD thesis. They could also be reported in future publications and conference presentations. If you would like a copy of the results you can contact the main researcher who will provide you with one in due course.

Thank you

Thank you for taking the time to read this Information Letter. If you decide to take part in the study I will ask you to sign the Consent Form.

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PARTICIPANT INFORMATION LETTER

Main Researcher: Sofia Chantziara
E-mail: SC714@kent.ac.uk
Telephone: (01634)202920

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism and their parents.

My name is Sofia Chantziara and I am a PhD student in Medway School of Pharmacy (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill). I want to invite you to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for you. I will describe the study and go through this Information Letter. If you decide to take part I will then ask you to sign a Consent Form.

Why are you doing this study?

I am doing this study because I want to understand what skills young people with autism at your age need, in order to live independently after they leave school and also what is the best way to teach them these skills.

Why did you contact me?

I want to talk to young people with autism who are in the age groups 16-21.

Do I have to take part?

NO! It is up to you to decide if you want to take part. You can say "YES" or you can say "NO" and your decision will not affect any of the services you receive.

What will happen to me if I want to take part?

If you want to take part I will invite you to talk to me. We will read this information letter together and we will talk about the study. Then I will ask you some questions to make sure that you understand what you are going to do in this study. If you understand what you are going to do in this study then you can take part.

What will happen to me if I take part?

I you take part I will invite you to talk to me. I will ask you questions about what you want to do after you leave school and what are the skills that you need in order to achieve your goals. There are no right or wrong answers. The discussion will last about 30-45 minutes and will be audio recorded.

Could bad things happen if I take part in the study?

I am interested in hearing everything you may feel about becoming an adult. If you find some things difficult to talk about that is OK. I want you to feel comfortable.

Could the study help me?

The study will not help you directly but your answers will help researchers, parents and teachers better understand the needs of

Who is organizing the study?

Medway School of Pharmacy is organizing and funding the study.

Who has reviewed the study?

The Medway School of Pharmacy Ethics Committee has reviewed and approved the study

What if I have a question?

If something is not clear to you and you want to ask questions you should contact Sofia (contact details on page 1) who will do her best to answer your questions or her supervisor Alison (E-mail: amb54@kent.ac.uk. Telephone: (01634) 893 944)

What if I want to complain?

If you have a complaint you can contact Sarah Corlett (E-mail: S.A.Corlett@kent.ac.uk. Telephone (01634) 88 8909) who is the Chair of the Ethics Committee in Medway School of Pharmacy.

What will happen if I do not want to carry on with the study?

You can stop taking part anytime, before or during the interview and no one will try to stop you or ask you to give any reasons for your decision.

Will my participation in the study be kept confidential?

Your confidentiality remains an obligation for us before and after the interview. We want you to know that:

Personal data in paper format will be locked in a secure filling cabinet in the University for 5 years and then will be shredded.

All audio recordings will be destroyed after they have been transcribed and analysed.

In all written documents your will be referred to as "*Participant 1 young person, age, male/female*", "*Participant 2 young person, age, male/female*"...etc and no one will be able to identify you

Authorised people (researchers, examiners, supervisors, regulatory authorities) could look at the data but they will not be able to identify you.

If you tell me something that may mean that you or someone else is in danger then I will have to talk to people who will be able to help you.

What will happen to the results of the study?

When I am finished with this study I will write a report about what we learned. This report will not include your name or that you were in the study. If you want a copy of the report you can e-mail me (contact details on page 1) and I will send you one.

Thank you

Thank you for taking the time to read this Information Letter. If you agree to take part I will then' ask you to sign the Consent Form.

Appendix B_7
Consent Form
Study 1: Interviews

medway school of pharmacy

PARTICIPANT CONSENT FORM

STUDY TITLE: PASSPORT TO LIFE: Investigating the need for life skills training among young people with autism and their parents.

Please write your initials in the box

1. I confirm I have read and understood the Information Letter for the Passport to Life study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time before or during the interview without giving any reason. (If you wish to withdraw from the study you should contact Sofia Chantziara.Telephone:01634202920). ☐

3. I understand that my responses will be anonymized before analysis. I give permission for members of the research team to have access to my anonymized responses. I also give permission for members of the research team to publish anonymized direct quotes. ☐

4. I agree to take part in the above research project. ☐

Name of participant	Date	Signature
Sofia Chantziara		
Name of person taking consent	Date	Signature
Sofia Chantziara		
Lead researcher	Date	Signature

medway school of pharmacy

PARENTAL REQUEST LETTER

Main Researcher: Sofia Chantziara
Email: SC714@kent.ac.uk
Telephone: (01634)202920

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism and their carers

My name is Sofia Chantziara and I am a PhD student in Medway School of Pharmacy (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill). I want to invite your child to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for your child. I will describe the study and go through this Information Letter. If you agree for your child to take part I will then ask you to sign a Consent Form.

What is the purpose of the study?

The aim of the study is to investigate the needs of young people with autism along with the needs of their parents/legal guardians for a successful transition into adulthood.

Why I have been contacted?

We want to recruit young people with a diagnosis of Autism, Asperger Syndrome (AS) or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) who also meet the following criteria:

1. Are in the age groups 11-15
2. Attending a secondary educational setting that caters for pupils with no global learning disability
3. No intellectual disability
4. Have good verbal ability

If your child meets the above criteria he/she can take part in the study.

Does my child have to take part?

No! Participation is entirely voluntary and your decision will not affect any of the services that you and your child are receiving.

What will happen to my child if I allow him/her take part?

I will invite your child to attend an interview. I will ask your child questions about his/her future aspirations and the skills he/she needs in order to achieve them. Interviews will last 30-45 minutes and will be audio recorded. If your child is in the age group 11-15 years he/she will have the option to do either a face to face interview or alternatively we can use Skype, phone or instant messaging (SKYPE/e-mails). Let me know which option you would prefer.

What are the possible risks and disadvantages of taking part?
There are no major risks to taking part in this study. There is a small possibility that your child may feel anxious or upset talking about his/her needs and the future. I will take every step necessary to minimize any feelings of discomfort during the interview.

What are the possible benefits of taking part?
Your child will receive a 10£ AMAZON voucher. The collective study results may also benefit young people with autism in the future as they will raise awareness about their needs and could inform the design of a life skills intervention.

Who is organizing the research?
Medway School of Pharmacy is organizing and funding the research.

Who has reviewed the study?
The Medway School of Pharmacy Ethics Committee has reviewed and approved this study.

What if I have a question?
If something is not clear to you and you want to ask questions you should contact Sofia Chantziara (contact details on page 1) who will do her best to answer your questions or her supervisor Dr Alison Bratt (E-mail: amb54@kent.ac.uk.Telephone: (01634) 892 944).

What if I want to complain?
If you have a complaint you should contact Dr Sarah Corlett (E-mail: S.A.Corlett@kent.ac.uk. Telephone (0)1634 88 8909) who is the Chair of the Ethics Committee in Medway School of Pharmacy.

What will happen if my child does not want to carry on with the study?
Your child is free to withdraw anytime, before or during the interview and no one will attempt to stop him/her or ask you and your child to give any reasons for your decisions.

Will my child's participation in the study be kept confidential?
The confidentiality of your child remains an obligation for us before and after the interview. We want you to know that:

- Personal data in paper format will be locked in a secure filling cabinet in the University for 5 years and then will be shredded.

- All audio recordings will be destroyed after they have been transcribed and analysed.

- In all written documents you child will be referred to as "*Participant 1 young person male/female", "Participant 2 young person male/female"* …etc and no one will be able to identify him/her. Interviews in the form of instant messaging will be treated as transcripts and will be fully anonymized with participants being referred to as "*Young Person Participant 1 male/female*" etc.

- Authorised people (researchers, examiners, supervisors, regulatory authorities) could look at the data but they will not be able to identify your child.

- University will keep the anonymised data for use in future studies approved by an appropriate Research Ethics Committee.

However, if your child during the interviews talks about incidents of abuse or other illegal act then the researcher is required to break confidentiality and inform statutory agencies.

What will happen to the results of the study?
The results will be presented in a PhD Thesis. They could also be reported in future publications and conference presentations. If you want a copy of the results you can contact the main researcher who will provide you with one in due course.

Thank you
Thank you for taking the time to read this Information Letter. If you are happy for your child to take part in the study I will ask you to sign the Consent Form. I will also ask your child to complete an Assent Form.

Appendix B9
Parental Consent Form
Study 1: Interviews

medway school of pharmacy

PARENTAL CONSENT FORM

STUDY TITLE: PASSPORT TO LIFE: Investigating the need for life skills training among young people with autism and their carers

Please write your initials in the box

5. I confirm I have read and understood the Information Letter for the Passport to Life study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

6. I understand that my child's participation is voluntary and that my child is free to withdraw at any time before or during the interview without giving any reason. (If you wish to withdraw your child from the study you should contact Sofia Chantziara. Telephone:01634202920). ☐

7. I understand that my child's responses will be anonymized before analysis. I give permission for members of the research team to have access to these anonymized responses. I also give permission for members of the research team to publish anonymized direct quotes. ☐

8. I agree for my child to take part in the above research project. ☐

______________________	______________________	______________________
Name of participant	Date	Signature
Sofia Chantziara	______________________	______________________
Name of person taking consent	Date	Signature
Sofia Chantziara	______________________	______________________
Lead researcher	Date	Signature

medway school of pharmacy

ASSENT FORM

Main Researcher: Sofia Chantziara

Email: SC714@kent.ac.uk
Telephone:(01634)202920

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism and their parents.

My name is Sofia Chantziara and I am a student. I want to invite you to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for you. Please talk with your parents before you decide if you want to participate.

Why are you doing this study?

I am doing this study because I want to understand what are the skills that young people with autism at your age need in order to live independently after they leave school.

Appendix B_{10}
Assent Form
Study 1: Interviews

Why did you contact me?

I want to ask some questions to young people with autism.

Do I have to take part?

You can say “YES” or you can say “NO”. No one will be upset if you say “NO”. I will also ask your parents to give their permission for you to take part in this study. But even if your parents say “YES” you can still say “NO” and decide not to be in the study.

What will happen to me if I take part?

If you decide to take part I will invite you to meet with me so that we can talk. I will ask you some questions and you will give your answers out loud. I will ask you questions about what you want to do after you leave school. There are no right or wrong answers. Our discussion will last about 30-45 minutes and I will audio record our discussion.

If you find it difficult to meet me that is OK. We can talk on the phone or on Skype. We can also use messages.

Could bad things happen if I take part in the study?

I am interested in hearing everything you may feel about becoming an adult. If you find some things difficult to talk about that is OK. I want you to feel comfortable

Could the study help me?

The study will not help you directly but your answers will help researchers, parents and teachers better understand the needs of young people with autism.

What will happen if I don't want to carry on with the study?

It is OK to say yes and change your mind later. If you decide to stop after we begin, that's okay too.

Appendix B10
Assent Form
Study 1: Interviews

Will other people know that I have taken part in study?

I will not tell anyone your name or that you were in the study unless I find out something that may mean you or someone else is in danger. Then I will have to tell people who will be able to help you.

What will happen to the results of the study?

When I am finished with this study I will write a report about what we learned. This report will not include your name or that you were in the study.

If you want to be in the study, please write your name below. This shows that you want to take part.

☐

____________________________________ ___

(Write your name here) (Tick the box)

Appendix B_{10}
Assent Form
Study 1: Interviews

Date: ___________________________

______

Appendix C_1
Approval Letter
Study 2: Focus Groups

medway school of pharmacy

8th December 2016

Your application for amendments to the project entitled *Passport to Life 2nd Study* has now been considered on behalf of the Medway School of Pharmacy School Research Ethics Committee (SREC).
I am pleased to inform you that your study has been approved, with immediate effect.

I must remind you of the following:

7. that if you are intending to work unaccompanied with children or with vulnerable adults, you will need to apply for a DBS check; the project must be conducted under the supervision of someone who has an up-to-date DBS check; you must not be in the presence of children alone except if you have completed a DBS check;
8. that you must comply with the Data Protection Act (1998);
9. that you must comply throughout the conduct of the study with good research practice standards;
10. If you are completing this project off site, you must obtain prior approval from relevant authorities and adhere to the MSOP off site protocol.
11. to refer any amendment to the protocol to the School Research Ethics Committee (SREC) for approval.
12. You are required to complete an annual monitoring report or end of project report and submit to j.mowbray@kent.ac.uk

Yours sincerely

Dr Sarah Corlett

Appendix C2
Gatekeeper Invitation Letter
Study 2: Focus Groups

medway school of pharmacy

Invitation to take part in research
Main Researcher: Sofia Chantziara
Email: SC714@kent.ac.uk
Telephone: (01634)202920

Dear < Head Teacher's name >,

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism

My name is Sofia Chantziara and I am a PhD student (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill) in Medway School of Pharmacy. I want to invite your school to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for your school.

What is the purpose of the study?
The aim of the study is to investigate the types of life skills training that are offered by schools to young people with autism in relation to adulthood transition. Also, the views of education providers regarding the current provisions and their recommendations for future improvements.

Do you have to take part?
No! Participation is entirely voluntary.

What will happen if you decide to take part?
If your school decides to participate I will invite 3-6 education providers who are members of your staff to take part in a focus group. I will ask them questions regarding the types of life skills training that your school offers and also their views regarding the current provisions and their recommendations for future improvements. The focus group will last 60 minutes and will be audio recorded. If possible, the focus group would ideally take place at your school, as it is the most convenient option for your staff.

If less than 3 members of your staff express an interest to participate in the study they could be asked to join a focus group of education providers from different schools. In this instance focus groups will take place in Medway School of Pharmacy (Central Avenue, Chatham Maritime, Kent, ME4 4TB or visit http://www.msp.ac.uk/ for map and directions) and travelling expenses will be covered.

What are the possible risks and disadvantages of taking part?
There are no major risks to taking part in this study. There is a small possibility that members of staff may feel distressed talking about their experience of working with pupils with autism. I will take every step necessary to minimize

any feelings of discomfort during the focus group. I can also direct them to specialist support via NAS.

Will the study help your school?
The study will not help your school directly. The collective study results may benefit young people with autism along with education providers in the future as they could help us learn more the provision of life skills training offered in schools and understand what should be included in a life skills intervention package.

Who is organizing the research?
Medway School of Pharmacy is organizing and funding the research.

Who has reviewed the study?
The Medway School of Pharmacy Ethics Committee has reviewed and approved the study.

What if you have a question?
If something is not clear to you and you want to ask questions you should contact Sofia Chantziara (contact details on page 1) who will do her best to answer your questions or her supervisor Dr Alison Bratt (E-mail: amb54@kent.ac.uk.Telephone: (01634) 892 944).

What do you need to do if you decide to take part?
In this e-mail you will find attached an Information Letter and Consent Form for the potential participants. You will also find attached a Gatekeeper Information Letter and Gatekeeper Consent Form that you should sign if you decide to take part in the study.
If you agree for your school to participate I would appreciate it if you could provide me with the contact details of a member of staff who I can liaise with during the recruitment phase. Sofia Chantziara, who is the main researcher, will call you in a week to discuss Passport to Life further and to find out whether you would like to be involved.

Yours Sincerely,

Sofia Chantziara

Appendix C_3
Gatekeeper Information Letter
Study 2: Focus Groups

medway school of pharmacy

GATEKEEPER INFORMATION LETTER

The term **"gatekeeper"** is used in the study documentation to mean "Persons who are able to arbitrate access to a social field setting (education providers who support pupils with ASDs)

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism.

Lead Investigator: Sofia Chantziara
Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill

Why is this study being done?

We are doing this study because we want to investigate:
a) The types of life skills training in relation to adulthood transition that are provided by schools to young people with autism.
b) Views of education providers regarding the current provisions
c) Recommendations from education providers for future improvements.

What we are requesting of you as a study gatekeeper.

We are requesting if your school would please be willing to act as a facilitator of data collection by allowing access to your members to whom study materials may be distributed? We request that you designate a member of staff who will be available to liaise with Sofia Chantziara and e-mail Information Letters and Consent Forms to education providers who are members of your staff, on the basis that Sofia Chantziara provides all materials. We also ask to use your premises to conduct the focus groups.

How will data be collected?

Data will be collected from education providers through focus groups. The minimum number of focus groups we would like to run in your school is one and the maximum two. Each focus group will include 3-6 participants and will last 50-60 minutes. In the event where less than 3 members of your staff express an interest to participate in the study they could be asked to join a focus group of education providers from different schools. In this instance focus groups will take place in Medway School of Pharmacy (Central Avenue, Chatham Maritime, Kent, ME4 4TB or visit http://www.msp.ac.uk/ for map and directions) and travelling expenses will be covered.

How will participant anonymity be upheld?

Consent Forms will be collected by Sofia Chantziara on the day of the focus group. The confidentiality of the participants remains an obligation for us before and after the focus groups. We would also like to inform you that: 1) Recordings of the focus groups will be destroyed after they have been transcribed and analysed. 2) Personal data in paper format, including consent forms, will be locked in a secure filling cabinet in the University for 5 years and then will be shredded 3) Transcripts of the focus groups will be fully anonymized and no one will be able to identify individual participants.

How will the data be used? What will happen to the results?

Findings will help the researchers understand life skills provision in schools and what should be included in a life skills intervention package. The results will also be presented in a PhD Thesis. They could also be reported in future publications and conference presentations. One A4 page summary of the results will be sent to national organizations, such as AUTISTICA and NAS, to inform them about the findings and the implications they may have for research and practice. Sofia Chantziara will also provide copies of 2 A4 pages summary to the gatekeeper that can be distributed to members of staff.

Do I have to take part?

No, it is up to you to decide whether or not to take part as a study gatekeeper. If you decide not to take part there will be no implications for you.

Are there any risks if I take part?

There are no risks to your taking part in this study. There is the time taken in distributing Invitation Letters and Consent Forms to members of your staff and also allowing Sofia Chantziara to use your premises, which we would fully appreciate.

Are there any benefits if I take part?

There will be no direct benefits to your school. We believe that the overall findings of this study could provide more understanding around the needs of young people with autism and could help us design a life skills intervention package.

Will anyone know that I’ve taken part?

No. The gatekeeper will remain anonymous.

Who is organizing the research?

Medway School of Pharmacy is organizing and funding the research*.*

Who has reviewed the study?

The Medway School of Pharmacy Ethics Committee has reviewed and approved the study*.*

Who should I contact if I want to know more about the study?

Study Principal Investigator: Sofia Chantziara, Medway School of Pharmacy, Central Avenue, Chatham Maritime, Kent, ME4 4TB.
Tel:(01634)202920, E-mail: SC714@kent.ac.uk).

Appendix C_4
Gatekeeper Consent Form
Study 2: Focus Groups

medway school of pharmacy

GATEKEEPER CONSENT FORM

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism.

Lead Investigator: Sofia Chantziara

I have read and understood the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial Here
I understand that my participation, acting as a representative of our school, is voluntary and that I am free to withdraw at any time, without giving a reason.	Initial Here
I understand that any personal information collected from focus groups during the study will be anonymised and remain confidential.	Initial Here
I agree, on behalf of the school (title) ____________________ to act as gatekeeper to this study. I agree to distribute Information Letters and Consent Forms to education providers on behalf of the study lead investigator, Sofia Chantziara.	Initial Here
I agree to allow the lead investigator to conduct focus groups at our premises.	Initial Here

Name of Participant (Print)

Signature Date

Name of Researcher (Print) Sofia Chantziara

Signature Date

medway school of pharmacy

PARTICIPANT INFORMATION LETTER

Main Researcher: Sofia Chantziara
Email: SC714@kent.ac.uk
Telephone: (01634)202920

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism.

My name is Sofia Chantziara and I am a PhD student (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill) in Medway School of Pharmacy. I want to invite you to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for you. I will describe the study and go through this Information Letter. If you agree to take part, I will then ask you to sign a Consent Form.

What is the purpose of the study?

The aim of the study is to investigate the types of life skills training that are offered by schools to young people with autism in relation to adulthood transition. Also, the study will seek the views of education providers regarding the current provisions and their recommendations for future improvements.

Why have I been contacted?

I want to talk to education providers. In order for you to participate in the study you should have a least one year experience of working with pupils with autism in the age groups 11 years old and above who are on the high functioning end of the spectrum.

Do I have to take part?

No! Participation is entirely voluntary.

What will happen to me if I take part?

If you decide to participate I will invite you to attend a focus group with 2-5 education providers from your school. I will ask you questions regarding the types of life skills training that your school offers and also your views regarding the current provisions and your recommendations for future improvements. If possible, the focus group would take place at your school, as it is the most convenient option for you. In the event where less than 3 members of staff in your school express an interest to participate you could be asked to join a focus group of education providers from different schools. In this instance the focus group will take place in Medway School of Pharmacy (Central Avenue, Chatham Maritime, Kent, ME4 4TB or visit http://www.msp.ac.uk/ for map and directions) and travelling expenses will be covered.

What are the possible risks and disadvantages of taking part?

There are no major risks to taking part in this study. There is a small possibility that you may feel distressed talking about your experience of working with pupils with autism. I will take every step necessary to minimize any feelings of discomfort during the focus group. I can also direct you to specialist support via NAS.

Will the study help me?
The study will not help you directly. The collective study results may benefit young people with autism and education providers in the future as they could help us understand life skills provision in schools and what should be included in a life skills intervention package.

Who is organizing the research?
Medway School of Pharmacy is organizing and funding the research.

Who has reviewed the study?
The Medway School of Pharmacy Ethics Committee has reviewed and approved the study.

What if I have a question?
If something is not clear to you and you want to ask questions you should contact Sofia Chantziara (contact details on page 1) who will do her best to answer your questions or her supervisor Dr Alison Bratt (E-mail: amb54@kent.ac.uk.Telephone: (01634) 892 944).

What if I want to complain?
If you have a complaint you can contact Dr Sarah Corlett (E-mail: S.A.Corlett@kent.ac.uk. Telephone: (01634) 88 8909) who is the Chair of the Ethics Committee in Medway School of Pharmacy.

What will happen if I don't want to carry on with the study?
You are free to withdraw any time before or during the focus group and no one will attempt to stop you or ask you to give any reasons for your decision. However, if you decide to withdraw during the focus group your contribution up to the point of withdrawal will remain in the recording and transcript.

Will my participation in the study be kept confidential?
Your confidentiality remains an obligation for us before and after the focus group. We want you to know that:

- Personal data in paper format will be locked in a secure filling cabinet in the University for 5 years and then will be shredded.
- All audio recordings will be destroyed after they have been transcribed and analysed.
- In all transcripts of the focus group you will be referred to as "*Participant (teacher/teacher assistant etc) male/female*" etc and no one will be able to identify you.
- Authorised people (researchers, examiners, supervisors, regulatory authorities) could look at the data but they will not be able to identify you.
- University will keep the anonymised data for use in future studies approved by an appropriate research ethics committee.

What will happen to the results of the study?

The results will be presented in a PhD thesis. They could also be reported in future publications and conference presentations. If you would like a copy of the results you can contact Sofia Chantziara who will provide you with one in due course.

Thank you

Thank you for taking the time to read this Information Letter. If you decide to take part in the study I will ask you to sign the Consent Form on the day of the focus group

Appendix C6
Participant Consent Form
Study 2: Focus Groups

medway school of pharmacy

PARTICIPANT CONSENT FORM
STUDY TITLE: PASSPORT TO LIFE: Investigating the need for life skills training among young people with autism.

Please write your initials in the box

I confirm I have read and understood the Information Letter for the Passport to Life study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time before or during the focus group without giving any reasons. (If you wish to withdraw from the study you should contact Sofia Chantziara.Telephone:01634202920). ☐

I agree to the focus group being audio recorded. ☐

I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have access to my anonymised responses. I also give permission for members of the research team to publish anonymised direct quotes. ☐

Name of Participant (Print) ____________________

Signature Date

____

Name of Researcher (Print) Sofia Chantziara

____

Signature Date

____

Appendix C_6
Participant Consent Form
Study 2: Focus Groups

Appendix D_1
Approval Letter
Study 3: Cross-sectional survey

medway school of pharmacy

10th October 2017

Dear Sofia

Your application for ethics approval for the project Passport to Life-third study has now been considered on behalf of the Medway School of Pharmacy School Research Ethics Committee (SREC).

I am pleased to inform you that your study has been approved, with immediate effect.

I must remind you of the following:

1. that if you are intending to work unaccompanied with children or with vulnerable adults, you will need to apply for a DBS check; the project must be conducted under the supervision of someone who has an up-to-date DBS check; you must not be in the presence of children alone except if you have completed a DBS check;
2. that you must comply with the Data Protection Act (1998);
3. that you must comply throughout the conduct of the study with good research practice standards;
4. If you are completing this project off site, you must obtain prior approval from relevant authorities and adhere to the MSOP off site protocol.
5. to refer any amendment to the protocol to the School Research Ethics Committee (SREC) for approval.
6. You are required to complete an annual monitoring report or end of project report and submit to j.mowbray@kent.ac.uk

Yours sincerely

Dr Sarah Corlett

medway school of pharmacy

Invitation to take part in research

Lead Investigator: Sofia Chantziara

Email: SC714@kent.ac.uk

Telephone: (01634)202920

Dear Sir/Madam,

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism

My name is Sofia Chantziara and I am a PhD student (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill**)** in Medway School of Pharmacy. I am writing to you as <head/assistant head of XXX educational establishment> because I want to invite your educational establishment to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for your educational establishment.

What is this study being done?

The aim of this study is to investigate the views and experiences of professionals and parents/carers in relation to life skills training that is available to young people with Autism Spectrum Disorders (ASDs). We propose to do this through the use of two anonymous questionnaires, one aimed at professionals and one aimed at parents/carers. The questionnaires will include questions about the challenges that young people with ASDs face; the life skills training that is available to them; types of support that they consider beneficial.

What will happen if you decide to take part?

If you decide to take part we will ask you to e-mail an Invitation/Information Letter that contains a link to the online questionnaires to members of your staff, who work in a learning support or educational capacity, and parents/carers of your pupils. We also ask you to e-mail a reminder Invitation Letter two weeks after the beginning of the study. We will also request from you to allow the lead investigator, if needed, to make visits to your premises from 1/10/2017 until 1/12/2017 in order to distribute paper questionnaires to parents/carers of pupils and members of your staff. Visits can take place during lunch breaks, when members of staff can be reached or at the end of the school day when parents/carers will be collecting the pupils. The lead investigator will inform you whether this will be necessary.

Who is organizing the research?
Medway School of Pharmacy is organizing and funding the research*.*

Who has reviewed the study?
The Medway School of Pharmacy Ethics Committee has reviewed and approved the study*.*

What if you have a question?
If something is not clear to you and you want to ask questions you should contact Sofia Chantziara (contact details on page 1) who will do her best to answer your questions or her supervisor Dr Alison Bratt (E-mail: amb54@kent.ac.uk.Telephone: (01634) 892 944).

What do you need to do if you decide to take part?
In this e-mail you will find attached Word versions of the two questionnaires, a Feedback Form and the Invitation/Information Letter that will direct participants to the online questionnaires. You will also find attached a Gatekeeper Information Letter, that will provide you with more details about the study, and a Gatekeeper Consent Form that you should sign if you decide to take part.
Yours Sincerely,

Kind Regards,
Sofia Chantziara

medway school of pharmacy

GATEKEEPER INFORMATION LETTER

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism.
Lead Investigator: Sofia Chantziara
Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill

Why is this study being done?

The aim of this study is to investigate the views and experiences of professionals and parents/carers in relation to life skills training that is available to young people with Autism Spectrum Disorders (ASDs).

What are we requesting of you?

We are requesting if your educational establishment would please be willing to act as a facilitator of data collection by allowing access to your staff and parents/carers of your pupils to whom study materials may be distributed? We request if you would be willing to e-mail an Invitation/Information Letter that contains a link to the online questionnaires or distribute paper questionnaires to members of your staff, who work in a learning support or educational capacity, and parents/carers of your pupils on the basis that the lead investigator supplies all materials. We ask you to e-mail a reminder Invitation/Information Letter two weeks after the beginning of the study. We also ask you to allow the lead investigator, if needed, to make visits to your premises from 1/10/2017 until 1/12/2017 in order to distribute paper questionnaires to parents/carers of your pupils and members of staff. Visits can take place during lunch breaks, when members of staff can be reached or at the end of the school day when parents/carers will be collecting the pupils. The visits will take place on dates that are most convenient for you. The lead investigator will inform you whether this will be necessary.

How will data be collected?

Data will be collected through the use of two anonymous questionnaires, one designed for parents/carers and one for professionals. The questionnaires will include questions about the challenges that young people with ASDs face as they transition to adulthood; the life skills training that is available to them; types of support that they consider beneficial. Each questionnaire will take around 15 minutes to complete. Participants will also be asked to complete a short Feedback Form to provide their comments and suggestions on the questionnaires.

How will participant anonymity be upheld?

No identifiable personal information will be collected in the course of this study, as all questionnaires will be anonymous.

How will the data be used? What will happen to the results?

Findings will help the researchers design a life skills intervention package for young people with ASDs. The results will also be presented in a PhD Thesis. They could also be reported in future publications and conference presentations. One A4 page summary of the results will be sent to national organizations, such as AUTISTICA and National Autistic Society, to inform them about the findings and the implications they may have for research and practice. Sofia Chantziara will also provide copies of a 2 A4 page summary of the results to the gatekeepers that can be distributed to their members of staff and parents/carers.

Do I have to take part?

No, it is up to you to decide whether or not to take part as a study gatekeeper. If you decide not to take part there will be no implications for you.

Are there any risks if I take part?

There are no risks to your taking part in this study. There is the time taken in distributing Invitation/Information Letters to members of your staff and parents/carers and also allowing Sofia Chantziara to visit your premises, which we would fully appreciate.

Are there any benefits if I take part?

There will be no direct benefits to your educational establishment. We believe that the overall findings of this study could provide more understanding around the needs of young people with ASDs and could help us design a life skills intervention package.

Will anyone know that I've taken part?

No. Gatekeepers will remain anonymous.

Who is organizing the research?

Medway School of Pharmacy is organizing and funding the research*.*

Who has reviewed the study?

The Medway School of Pharmacy Ethics Committee has reviewed and approved the study*.*

Who should I contact if I want to know more about the study?

Study Principal Investigator: Sofia Chantziara, Medway School of Pharmacy, Central Avenue, Chatham Maritime, Kent, ME4 4TB.
Tel:(01634)202920, E-mail: SC714@kent.ac.uk).

Appendix D_4
Gatekeeper Consent Form-Schools
Study 3: Cross-sectional survey

medway school of pharmacy

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism.

Lead Investigator: Sofia Chantziara

I have read and understood the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial Here
I understand that my participation, acting as a representative of our educational establishment, is voluntary and that I am free to withdraw at any time, without giving a reason.	Initial Here
I understand that no personal information will be collected during the course of this study	Initial Here
I agree, on behalf of (educational establishment) ____________________ to act as gatekeeper to this study. I agree to e-mail an Invitation/Information Letter to members of staff, who work in a learning support or educational capacity and parents/ carers of our pupils and a reminder Invitation/Information Letter two weeks after the beginning of the study.	Initial Here
I agree, if requested, to allow the lead researcher to make visits to our premises from 1/10/2017 until 1/12/2017 in order to distribute questionnaires to members of staff and parents/carers of our pupils.	Initial Here

Name of Participant (Print)

____

Signature   Date

____

Name of Researcher (Print) Sofia Chantziara

____

Signature Date

Appendix D5
Participant Invitation/Invitation Letter
Study 3: Cross-sectional survey

medway school of pharmacy

Passport to Life: Investigating the need for life skills training among young people with autism

Dear parents and professionals,

We would like to invite you take part in a new research study organised by Medway School of Pharmacy. The aim of this study is to investigate the views and experiences of professionals and parents/carers in relation to life skills training that is available to young people with Autism Spectrum Disorders (ASDs). This is an online survey and is aimed at:

- Parents/carers of young people with Autism Spectrum Disorders (ASDs) without intellectual disability, who are in the age groups 11-18 and also attend a secondary or further education establishment that caters for pupils without intellectual disability
- Teachers along with other professionals who work in a learning support or educational capacity in secondary or further education establishments that cater for pupils with ASDs aged between 11-18 years without intellectual disability
-

The survey is available at the URL:

The survey will take around 15 minutes to complete and is completely anonymous.
Thank you for taking the time to read this Invitation Letter. If you are interested in taking part please read the **following Information Letter** before accessing the questionnaire.

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medway school of pharmacy

Main Researcher: Sofia Chantziara
Email: SC714@kent.ac.uk
Telephone: (01634)202920

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism

My name is Sofia Chantziara and I am a PhD student (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill) in Medway School of Pharmacy. I want to invite you to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for you.

What is the purpose of the study?
The aim of this study is to investigate the views and experiences of professionals and parents/carers in relation to life skills training that is available to young people with Autism Spectrum Disorders (ASDs).

Who can take part in the study?
You can take part if you are:

- Parent/carer of at least one young person with Autism Spectrum Disorder (ASD) without intellectual disability, who is in the age groups 11-18 and also attends a secondary or further education establishment that caters for pupils without intellectual disability
- Teacher or other professional who works in a learning support or educational capacity in a secondary or further education establishment that caters for pupils with ASDs aged between 11-18 years without intellectual disability

Do I have to take part?
No! Participation is entirely voluntary and will not affect any of the services that you receive.

What will happen to me if I take part?
If you agree to take part I will ask you to complete an anonymous questionnaire. The questionnaire will include questions about the challenges that young people with ASDs face as they transition to adulthood; the life skills training that is available to them; types of support that they consider beneficial. The questionnaire will take around 15 minutes to complete. Your completion of the questionnaire is taken as your implied consent to participate.

What are the possible risks and disadvantages of taking part?
There is a small possibility that you may feel anxious or distressed recalling your experiences of living and working autism. In this instance I will advise you to visit the site of National Autistic Society http://www.autism.org.uk where you will find guidance and information on services you can access.

Will the study help me?
The study will not help you directly. The collective study results may benefit young people with ASDs in the future as they could raise awareness about their needs and could help us understand what should be included in a life skills intervention package.

Who is organizing the research?
Medway School of Pharmacy is organizing and funding the research.

Who has reviewed the study?
The Medway School of Pharmacy Ethics Committee has reviewed and approved the study.

What if I have a question?

If something is not clear to you and you want to ask questions you should contact Sofia Chantziara (contact details on page 1) who will do her best to answer your questions or her supervisor Dr Alison Bratt (E-mail: amb54@kent.ac.uk.Telephone: (01634) 892 944).

What if I want to complain?

If you have a complaint you can contact Dr Sarah Corlett (E-mail: S.A.Corlett@kent.ac.uk. Telephone: (01634) 88 8909) who is the Chair of the Ethics Committee in Medway School of Pharmacy.

Will my participation in the study be kept confidential?

Your participation is completely anonymous as no identifiable personal information will be collected in the course of this study. Organizations and educational establishments will not be able to identify individual participants from their responses.

What will happen to the results of the study?

The results will be presented in a PhD thesis. They could also be reported in future publications and conference presentations. A summary of the results will also be sent to national organizations such as AUTISTICA and National Autistic Society, to inform them about the findings and the implications they may have for research and practice. Organizations that have acted as gatekeepers for the study will also receive a 2 A4 page summary of the results which they can make available to their members.

What to do now

Thank you for taking the time to read this Information Letter. If you would like to participate in the study please go to the <URL> to access and complete the questionnaire. At the end of the questionnaire you will find a short Feedback Form. I would really appreciate it if you could take a few extra minutes complete the form and provide your comments and suggestions.

medway school of pharmacy

Invitation to take part in research

Lead Investigator: Sofia Chantziara

Email: SC714@kent.ac.uk

Telephone: (01634)202920

Dear Sir/Madam,

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism

My name is Sofia Chantziara and I am a PhD student (Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill**)** in Medway School of Pharmacy. I am writing to you as < XXX of the XXX organization> because I want to invite your organization to take part in my study. Before you decide I would like you to understand why I am doing this study and what it would involve for your organization.

What is this study being done?

The aim of this study is to investigate the views and experiences of professionals, who work in a learning support or educational capacity, and parents/carers in relation to life skills training that is available to young people with Autism Spectrum Disorders (ASDs). We propose to do this through the use of two anonymous questionnaires, one aimed at professionals and one aimed at parents/carers. The questionnaires will include questions about the challenges that young people with ASDs face as they transition to adulthood; the life skills training that is available to them; types of support that they consider beneficial.

What will happen if you decide to take part?

If you decide to take part we will ask you to make available an Invitation/Information Letter that contains a link to the online questionnaires to your members. You can either e-mail the Invitation/Information Letter to your members, advertise it on your website/newsletter or use any other means that you would consider suitable. If you decide to e-mail the Invitation/Information Letter to your members then we would like to request from you to send a reminder Invitation/Information Letter two weeks after the beginning of the study. We also ask you to allow the lead investigator, if needed, to visit events you are organizing from 1/10/2017 until 1/12/2017 in order to distribute paper questionnaires to the attendees. Again, the lead investigator will inform you whether this will be necessary.

Who is organizing the research?
Medway School of Pharmacy is organizing and funding the research.

Who has reviewed the study?
The Medway School of Pharmacy Ethics Committee has reviewed and approved the study.

What if you have a question?
If something is not clear to you and you want to ask questions you should contact Sofia Chantziara (contact details on page 1) who will do her best to answer your questions or her supervisor Dr Alison Bratt (E-mail: amb54@kent.ac.uk.Telephone: (01634) 892 944).

What do you need to do if you decide to take part?
In this e-mail you will find attached Word versions of the two questionnaires, a questionnaire Feedback Form and an Invitation/Information Letter that will direct participants to the online questionnaires. You will also find attached a Gatekeeper Information Letter, that will provide you with more details about the study, and a Gatekeeper Consent Form that you should sign if you decide to take part.

Yours Sincerely,

Sofia Chantziara

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GATEKEEPER INFORMATION LETTER

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism.
Lead Investigator: Sofia Chantziara
Supervisors: Dr Alison Bratt, Professor Janet Krska, Professor Peter McGill

Why is this study being done?

The aim of this study is to investigate the views and experiences of professionals who work in a learning support or educational capacity and parents/carers in relation to life skills training that is available to young people with Autism Spectrum Disorders (ASDs).

What are we requesting of you?

We are requesting if your organization would please be willing to act as a facilitator of data collection by allowing access to your members to whom study materials may be distributed? We request if you would be willing to make available an Invitation/Information Letter that contains a link to the online questionnaires to your members on the basis that the lead investigator supplies all materials. You can either e-mail the Invitation/Information Letter to your members, advertise it on your website/newsletter or use any other means that would consider suitable. If you decide to e-mail the Invitation/Information Letter to your members then we would like to request from you to send a reminder Invitation/Information Letter two weeks after the beginning of the study. We also ask you to allow the lead investigator, if needed, to visit events you are organizing from 1/10/2017 until 1/12/2017 in order to distribute paper questionnaires to the attendees. The visits will take place on dates that are most convenient for you. The lead investigator will inform you whether this will be necessary.

How will data be collected?

Data will be collected from your members through the use of two anonymous questionnaires, one designed for parents/carers and one for professionals. The questionnaires will include questions about the challenges that young people with ASDs face as they transition to adulthood; the life skills training that is available to them; types of support that they consider beneficial. Each questionnaire will take around 15 minutes to complete. Participants will also be asked to complete a short Feedback Form to provide their comments and suggestions on the questionnaires.

How will participant anonymity be upheld?

No identifiable personal data will be gathered in the course of this study, as all questionnaires will be anonymous.

How will the data be used? What will happen to the results?

Findings will help the researchers design a life skills intervention package for young people with ASDs. The results will also be presented in a PhD Thesis. They could also be reported in future publications and conference presentations. One A4 page summary of the results will be sent to national organizations, such as AUTISTICA and National Autistic Society, to inform them about the findings and the implications they may have for research and practice. Sofia Chantziara will also provide copies of 2 A4 page summary of the results to the gatekeeper that can be distributed to their members.

Do I have to take part?

No, it is up to you to decide whether or not to take part as a study gatekeeper. If you decide not to take part there will be no implications for you.

Are there any risks if I take part?

There are no risks to your taking part in this study. There is the time taken in making available Invitation/Information Letters to your members and also allowing Sofia Chantziara, if requested, to visit your events, which we would fully appreciate.

Are there any benefits if I take part?

There will be no direct benefits to your organisation. We believe that the overall findings of this study could provide more understanding around the transition needs of young people with ASDs and could help us design a life skills intervention package.

Will anyone know that I've taken part?

No. Gatekeepers will remain anonymous.

Who is organizing the research?

Medway School of Pharmacy is organizing and funding the research*.*

Who has reviewed the study?

The Medway School of Pharmacy Ethics Committee has reviewed and approved the study

.

Who should I contact if I want to know more about the study

Study Principal Investigator: Sofia Chantziara, Medway School of Pharmacy, Central Avenue, Chatham Maritime, Kent, ME4 4TB.Tel:(01634)202920, E-mail: SC714@kent.ac.uk).

Appendix D_8
Gatekeeper Consent Form-Organizations
Study 3: Cross-sectional survey

medway school of pharmacy

Study Title: Passport to Life: Investigating the need for life skills training among young people with autism.

Lead Investigator: Sofia Chantziara

I have read and understood the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	Initial Here
I understand that my participation, acting as a representative of our organization, is voluntary and that I am free to withdraw at any time, without giving a reason	Initial Here
I understand that no personal information will be collected during the course of this study	Initial Here
I agree, on behalf of (organization)____________________to act as gatekeeper to this study	Initial Here
I agree to make available an Invitation/Information Letter with link to the online questionnaire to our members. If I choose to e-mail the invitation /Information Letter I also agree to e-mail a reminder Invitation/Information Letter two weeks after the beginning of the study.	Initial Here
I also agree, if requested, to allow the lead investigator to visit our events from 1/10/2017 until 1/12/2017 in order to distribute paper questionnaires to the attendees.	Initial Here

Name of Participant (Print)

Signature Date

Name of Researcher (Print) Sofia Chantziara

Signature Date

Are you the parent/carer of at least one young person aged between 11-18 years diagnosed with Autism Spectrum Disorder (ASD) without co-occurring intellectual disability?

☐ Yes
☐ No

Does the young person attend a secondary or further education establishment that caters for pupils without co-occurring intellectual disability?

☐ Yes
☐ No

Thank you for taking the time to access the questionnaire and complete the first two questions. If your answer to either of these questions is **NO** please do not to complete the rest of the questionnaire.

Section A: Personal Information

1) What is your gender?

☐ Female
☐ Male

2) How many young people with an ASD diagnosis without intellectual disability who also attend a secondary or further education establishment that caters for pupils without co-occurring intellectual disability are in your family?

☐ 1
☐ 2
☐ 3
☐ more than 3

3) Can you state the gender and age of the young person(s) with ASD in your family?

Person 1: ☐ Female ☐ Male Age___________
Person 2: ☐ Female ☐ Male Age___________
Person 3: ☐ Female ☐ Male Age___________

If more than three young people with ASDs without intellectual disability who also attend a secondary or further education establishment that caters for pupils without co-occurring intellectual disability are in your family, please use the lines below to state their Gender and Age:

4) What type of educational establishment does the young person attend?

	Specialist school	Mainstream school	Mainstream school with a special unit	Grammar school	Independent school	Boarding school	Further Education College	Other (Please specify)
Person 1					Mainstream specialist			
Person 2					Mainstream specialist			
Person 3					Mainstream specialist			

If more than three young people with ASDs without intellectual disability are in your family, please use the lines below to provide information on the type of educational establishment they attend:

Section B: Perceived challenges

1) Using a scale between 1 for "not significant at all" and 5 for "very significant", please rate the level of difficulty that the young person experiences in the following areas:

a) Communication (examples: taking part in conversations; understanding humor)

	Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

If more than three young people with ASDs without intellectual disability are in your family, please use the lines below to rate their level of difficulty:

b) Daily living skills (examples: maintaining personal hygiene and appearance; handling money)

	Not significant at all	Slightly significant	significant	Fairly significant	Very significant	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

c) Peer relationships

	Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

d) Self-management (examples: anxiety; self-esteem; anger issues)

	Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

e) Romantic relationships

	Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

....

....

....

f) Social skills

	Not significant at all	Slightly significant	significant	Fairly significant	Very significant	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

....

....

....

2) Using a scale between 1 for “not optimistic at all” and 5 for “very optimistic” please rate how optimistic you feel about the young person achieving the following outcomes in adulthood:

a) Live independently in their own residence

	Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

If more than three young people with ASDs without intellectual disability are in your family, please use the lines below to rate how optimistic you feel:

....

....

....

b) Have a relationship with a partner

	Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

....

....

....

c) Complete a qualification in post-secondary education

	Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

....

....

....

d) Find and maintain paid employment (part time of full time)

	Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
Person 1	1	2	3	4	5	6
Person 2	1	2	3	4	5	6
Person 3	1	2	3	4	5	6

....

....

....

Section C: Offered training and support

Using a scale between 1 for "not at all satisfied" all" and 5 for "very satisfied", please rate your satisfaction with the life skill support that the young person has received from his/her educational establishment.

1) How satisfied are you with the support that your educational establishment provides around daily living skills?

	Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

If more than three young people with ASDs without intellectual disability are in your family, please use the lines below to rate your satisfaction:

----

2) How satisfied are you with the support that your educational establishment provides around peer relationships?

	Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

----

3) How satisfied are you with the support that your educational establishment provides around self-management?

	Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

----

4) How satisfied are you with the support that your educational establishment provides around communication skills?

	Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

5) How satisfied are you with the support that your educational establishment provides around social skills?

	Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

6) How satisfied are you with the communication between your educational establishment and parents/carers?

	Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

7) Using a scale between 1 for “strongly disagree” and 5 for “strongly agree”, please state your level of agreement with the following statements:

a) Our educational establishment adequately understands the needs of pupils with ASDs

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

If more than three young people with ASDs without intellectual disability are in your family, please use the lines below to state your level of agreement:

----

b) Our educational establishment provides support tailored to the individual needs of pupils with ASDs

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

----

c) Our educational establishment adequately prepares young people for meaningful employment

	Strongly disagree	Disagree	Neither Agree or disagree	Agree	Strongly agree
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

----

d) Our educational establishment adequately prepares young people for post-secondary education

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

----

e) Our educational establishment adequately prepares young people for independent living

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

f) Our educational establishment provides adequate sex and relationships education

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Person 1	1	2	3	4	5
Person 2	1	2	3	4	5
Person 3	1	2	3	4	5

8) How easy is it to identify and access support around life skills for the young person(s)?

Haven't tried	Not at all easy	Not very easy	Fairly easy	Easy	Very easy
1	2	3	4	5	6

9) Have you received support around life skills from any services other than your educational establishment?

☐ Yes
☐ No

10) If Yes please describe the service and the type of support you have received

Service 1

Service 2

Service 3 --

If you have accessed more than three services, please use the lines below to describe the service and the type of support you have received:

----

11) How did you identify and access that support (you can choose more than one option if you have accessed support from more than one service)?

☐ School organized it and it was provided within school
☐ School organized it and it was provided in a different location
☐ Recommendation from a health care professional (ex GP, Pediatrician).
☐ Privately organized and funded.
☐ Privately organized and was offered without charge by the provider.
☐ Directed through another service or organization (ex NAS).
☐ Other (Please specify) ………………………………………………………..

Section D: Desired training and support

1) What would you consider to be the most desirable method of delivering support around life skills within your educational establishment? Please rank your first 3 choices in a scale from 1 to 3 with 1 for what you consider most desirable to 3 for what you consider less desirable form of support.

☐ Mentoring/Befriending
☐ One to one support
☐ Group work
☐ Combination of one to one and group work

- ☐ Training delivered as part of the school curriculum
- ☐ Training provided through an online platform
- ☐
- ☐ Other (Please specify) ……………………………………………………….

2) What would you like the life skills training offered by your educational establishment to cover? Please rank the options bellow in a scale between 1 for what you consider most important and 9 for what you consider least important.

- ☐ Social-communication skills
- ☐ Peer relationships
- ☐ Romantic relationships
- ☐ Daily living skills
- ☐ Self-management
- ☐ Careers advice
- ☐ Preparation for post-secondary education
- ☐ Preparation for work placements
- ☐ Support with the process of university applications

3) On a scale of 1-10 with 1 being “not at all involved” and 10 being “very involved” what would you consider as a desirable level of parental involvement in the life skills training provided by your school?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Section E: Demographics

1) What is your ethnic group?

Choose one option that best describes your ethnic group or background

White

☐ English/Welsh/Scottish/Northern Irish/British
☐ Irish
☐ Gypsy or Irish Traveler
☐ Any other White background, please describe

Mixed/Multiple ethnic groups

☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed/Multiple ethnic background, please describe

---

Asian/Asian British

☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background, please describe

Black/ African/Caribbean/Black British

☐ African
☐ Caribbean
☐ Any other Black/African/Caribbean background, please describe

Other ethnic group

☐ Arab
☐ Any other ethnic group, please describe

---

2) What was your total household income before taxes during the past 12 months?

☐ Up to £11,501
☐ £11,501 to £45,000
☐ £45,001 to £150,00
☐ Over £150,000
☐ Prefer not to answer

3) What is the highest degree or educational level that you have completed?

☐ Secondary school or equivalent
☐ Vocational/Technical School
☐ Some college
☐ Bachelor's Degree
☐ Master's degree
☐ Doctoral Degree
☐ Prefer not to answer
☐ Other (Please specify)

"By completing and returning this questionnaire, you are giving your consent to be part of this study and for your data to be used as described in the participant information letter"

Are you a teacher or other member of staff who works in a learning support or educational capacity in a secondary or further education establishment that caters for pupils with Autism Spectrum Disorders (ASDs) aged between 11-18 years without co-occurring intellectual disability?

☐ Yes
☐ No

Thank you for taking the time to access the questionnaire and complete the first question. If your answer is **NO** then please do not to complete the rest of the questionnaire.

Section A: Personal information.

1) What is your gender?

☐ Female
☐ Male

2) What is your role?

☐ Teacher
☐ SEN Teacher
☐ Learning Mentor
☐ Teaching Assistant
☐ SENCO
☐ Other (Please specify) ____________________________

3) Where do you work?

☐ Mainstream school
☐ Mainstream school with a unit
☐ Grammar school
☐ Specialist school
☐ Mainstream independent school
☐ Specialist independent school
☐ Further Education College
☐ Boarding school
☐ Other (Please specify) ____________________________

Section B: Perceived challenges

1) Using a scale between 1 for "not significant at all" and 5 for "very significant", please rate the level of difficulty that your pupils with high functioning ASDs experience in the following areas:

a) Communication (examples: taking part in conversations; understanding humor)

Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
1	2	3	4	5	6

b) Daily living skills (examples: maintaining personal hygiene and appearance; handling money)

Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
1	2	3	4	5	6

c) Peer relationships

Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
1	2	3	4	5	6

d) Self-management (examples: anxiety; self-esteem; anger issues)

Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
1	2	3	4	5	6

e) Romantic relationships

Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
1	2	3	4	5	6

f) Social skills

Not significant at all	Slightly significant	Significant	Fairly significant	Very significant	No opinion
1	2	3	4	5	6

2) Using a scale of 1 for "not optimistic at all" and 5 for "very optimistic" please rate how optimistic you feel about your pupils with high functioning ASDs achieving the following outcomes in adulthood:

a) Live independently in their own residence

Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
1	2	3	4	5	6

b) Have a relationship with a partner

Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
1	2	3	4	5	6

c) Complete a qualification in post-secondary education

Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
1	2	3	4	5	6

d) Find and maintain paid employment (part time or full time)

Not optimistic at all	Slightly optimistic	Optimistic	Fairly optimistic	Very optimistic	No opinion
1	2	3	4	5	6

Section C: Offered training and support.

Using a scale between 1 for “not at all satisfied” all” and 5 for “very satisfied”, please rate your satisfaction with the life skill support that your educational establishment provides to pupils with high functioning ASDs.

1) How satisfied are you with the support that your educational establishment provides to pupils with high functioning ASDs around daily living skills?

Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
1	2	3	4	5

2) How satisfied are you with the support that your educational establishment provides to pupils with high functioning ASDs around peer relationships?

Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
1	2	3	4	5

3) How satisfied are you with the support that your school provides to pupils with high functioning ASDs around self-management?

Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
1	2	3	4	5

4) How satisfied are you with the support that your educational establishment provides to pupils with high functioning ASDs around communication skills?

Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
1	2	3	4	5

5) How satisfied are you with the support that your educational establishment provides to pupils with high functioning ASDs around social skills?

Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
1	2	3	4	5

6) How satisfied are you with the communication between your educational establishment and parents/carers of pupils with ASDs?

Not at all satisfied	Partly satisfied	Satisfied	More than satisfied	Very satisfied
1	2	3	4	5

7) Using a scale between 1 for "strongly disagree" and 5 for "strongly agree", please state your level of agreement with the following statements:

a) Our educational establishment adequately understands the specific needs of pupils with high functioning ASDs

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

b) Our educational establishment provides support tailored to the individual needs of pupils with high functioning ASDs

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

c) Our educational establishment adequately prepares pupils with high functioning ASDs for meaningful employment

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

d) Our educational establishment adequately prepares pupils with high functioning ASDs for post-secondary education

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

e) Our educational establishment adequately prepares pupils with high functioning ASDs for independent living

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

f) Our educational establishment provides adequate sex and relationships education to pupils with high functioning ASDs

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

8) Using a scale between 1 for “not confident at all” and 5 for “very confident”, please rate your confidence in assisting your pupils with high functioning ASDs with the following:

a) Daily living skills

Not confident at all	Somewhat confident	Confident	More than confident	Very confident
1	2	3	4	5

b) Social-communication Skills

Not confident at all	Somewhat confident	Confident	More than confident	Very confident
1	2	3	4	5

c) Peer relationships

Not confident at all	Somewhat confident	Confident	More than confident	Very confident
1	2	3	4	5

d) Self-management

Not confident at all	Somewhat confident	Confident	More than confident	Very confident
1	2	3	4	5

e) Romantic relationships

Not confident at all	Somewhat confident	Confident	More than confident	Very confident
1	2	3	4	5

f) Understand the specific needs of pupils with ASDs

Not confident at all	Somewhat confident	Confident	More than confident	Very confident
1	2	3	4	5

g) Respond to the individual needs of pupils with ASDs

Not confident at all	Somewhat confident	Confident	More than confident	Very confident
1	2	3	4	5

9) Using a scale between 0 for “not useful at all” and 5 for “very useful” please rate how useful you consider the following resources when you are assisting your pupils with high functioning ASDs with life skills:

a) Own skills and expertise

Not useful at all	Somewhat useful	Useful	More than useful	Very useful	No opinion
1	2	3	4	5	6

b) External services or resources (Please specify)

Not useful at all	Somewhat useful	Useful	More than useful	Very useful	No opinion
1	2	3	4	5	6

c) Resources developed within school (examples: training packages) (Please specify)

Not useful at all	Somewhat useful	Useful	More than useful	Very useful	No opinion
1	2	3	4	5	6

d) Taking part in external activities and projects (Please specify)

Not useful at all	Somewhat useful	Useful	More than useful	Very useful	No opinion
1	2	3	4	5	6

e) Links with the Local Community (Please specify)

Not useful at all	Somewhat useful	Useful	More than useful	Very useful	No opinion
1	2	3	4	5	6

f) After school clubs and activities available at school

Not useful at all	Somewhat useful	Useful	More than useful	Very useful	No opinion
1	2	3	4	5	6

10) Please describe any other resources that you may use:

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11) Do you feel that you need additional training or support to assist your pupils with high functioning ASDs with life skills?

☐ Yes
☐ No

12) If Yes please specify

Section C: Desired training and support

1) What would you consider to be the most desirable method of delivering support around life skills within your educational establishment? Please rank you first 3 choices in a scale from 1 to 3 with 1 for what you consider most desirable to 3 for what you consider less desirable form of support.

☐ Mentoring/Befriending
☐ One to one support
☐ Group work
☐ Combination of one to one and group work

☐ Training delivered as part of the school curriculum
☐ Training provided through an online platform
☐ Other (Please specify) ………………………………………………………….

2) What would you like the life skills training offered by your educational establishment to cover? Please rank the options bellow in a scale between 1 for what you consider most important and 9 for what you consider least important.

☐ Social-communication skills
☐ Peer relationships
☐ Romantic relationships
☐ Daily living Skills
☐ Self-management
☐ Careers advice
☐ Preparation for post-secondary education
☐ Preparation for work placements
☐ Support with the process of university applications

3) On a scale of 1-10 with 1 being "not at all involved" and 10 being "very involved" what would you consider as a desirable level of parental involvement in the life skills training provided by your school?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

"By completing and returning this questionnaire, you are giving your consent to be part of this study and for your data to be used as described in the participant information letter"

Appendix D_{11}
Social Validity Form
Study 3: Cross-sectional survey

Feedback Form

1) I understood what the questionnaire was about

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

2) The questionnaire took me around 15 minutes to complete

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

3) The instructions for answering the questions were clear and easy to understand

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

4) The questions were clear and easy to understand

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

5) The scales used to answer the questions were clear and easy to understand

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	2	3	4	5

6) Do you think there were other relevant issues that were not covered?

Yes ☐

No ☐

If Yes, please specify

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7) Were there any questions that you found hard to answer because the options you were given to choose from did not cover your opinion or how you felt?

Yes ☐
No ☐

If Yes, please describe them
