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UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Exploring intervention strategies and supports to promote mental wellbeing among individuals (aged 18-21) with ASD non-ID: The experiences of professionals in Cork/Kerry

Lynn Brosnan

CARL Research Project
in collaboration with
Aspect

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

Name of student(s):	Lynn Brosnan
Name of civil society organisation/community group:	Aspect
Name of community group liaison person:	Ms Yvonne Scriven
Academic supervisor(s):	Ms Nicola Maxwell
Name and year of course:	Bachelor Social Science Year 3
Date completed:	1st May 2018

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- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
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Abstract

In society today Autistic Spectrum Disorder is very much prevalent as a study conducted by DCU revealed that approximately 1% of the population is affected by it. The transition period to third-level/ further education is highlighted throughout the literature as being crucial and can have a severe impact on one's mental wellbeing, in particular for those with Asperger Syndrome. The NCSE explored in their research that by increasing student supports during this period, greater educational outcomes could be achieved as well as improved mental wellbeing.

The aim of this study is to explore the strategies and intervention which are employed by key workers in Aspect which promote mental wellbeing for their clients with AS during the transition.

The study is informed by an interpretive approach whereby the researcher conducted five semi-structured interviews through which key workers were asked about the work carried out in Aspect in relation to the transition period and also existing supports among higher education institutes.

From the primary research conducted, four themes were developed which were: 'Transition Period', 'Social Skills Deficit', 'Strategies used by key workers' and 'Existing Student Supports'. These themes had been similar to those which were explored in the literature review while also providing the researcher with new information which had not previously been explored.

The transition period, although being very much an individual experience, if supported, correctly can be a positive one. It emerged from the findings that the transition period and preparation for it needs to begin earlier and this may decrease stress on the client and promote mental wellbeing and a more positive experience in higher education.

Glossary of Terms

AS	Asperger Syndrome
ASD	Autistic Spectrum Disorder
CARL	Community Academic Research Link
CBR	Community Based Research
CBT	Cognitive Behavioural Therapy
CSO	Civil Society Organisation
DARE	Disability Access Route to Education
DBT	Dialectical Behavioural Therapy
DCU	Dublin City University
DSS	Disability Support Service
DSM	Diagnostic and Statistical Manual of Mental Disorders
EPSEN	Education for Persons with Special Education Needs
EU	European Union
HFA	High Functioning Autism
HSE	Health Service Executive
ICD	International Classification of Diseases
ID	Intellectual Disability
IEP	Individual Education Plans
IQ	Intelligence Quotient
NDA	National Disability Authority
NCSE	National Council for Special Education
PAR	Participatory Action Research
SREC	Social Research Ethics Committee
UCC	University College Cork
UNCRPD	United Nations Convention on the Rights of People with Disabilities
UN	United Nations

Chapter One: Introduction

1.1 Introduction

The intention of this piece of research is to explore a subject which is of personal interest and also is carried out in conjunction with CARL, Community Academic Research Link and Aspect. CARL gives opportunities to various voluntary or community organisations to put forward different research topics which students can then carry out this research on their behalf (Ucc.ie, 2017). Aspect is a service under the Cork Association of Autism, set up in 2007, which assists clients who have a diagnosis of Asperger's Syndrome (AS)/ Autistic Spectrum Disorder (ASD) without Intellectual Disabilities in Cork and Kerry. It uses a model of service centred on individualised support and intervention. The key-workers in Aspect use key strategies and interventions to assist their clients. It is client-centred which means that the client chooses which specific area they would like to work on with their assigned key worker. Some areas that may be worked on are independent living, education and employment. (Aspect Support Service, 2017).

1.2 Rationale

Autistic Spectrum Disorder is very prevalent in Irish society as seen in a study carried out in 2016 by DCU which saw results revealing that a minimum of 1% of the population is affected by autism (Sweeney, Staines and Boilson, 2016). It is widely researched in relation to how mental health issues may arise at this period of transition to further education, such as anxiety (Bellini, 2004), yet it is unknown whether adequate resources are available for those who struggle. This piece of research will focus on that critical point in young adulthood where a person is transitioning from adolescence and may be looking for additional needs and supports as they aim to further their education. In 2016, the NCSE commissioned a study where the findings revealed supports for individuals with ASD deteriorates greatly post-secondary education. The study commented that by improving supports there would be greater educational outcomes and mental wellbeing would be improved (NCSE, 2016). Autism will also be examined in terms of social functioning and the ability to cope in society especially in regards to socialisation and theory of mind. The

transition to furthering education will be examined and researched in regards to difficulties experienced by individuals with AS.

1.3 Research Aim

The aim of this research is to examine what particular supports are available for those who are transitioning from adolescence to adulthood with Asperger Syndrome (AS)/High Functioning Autism (HFA) in Cork in relation to furthering their education after second-level. This research has been conducted in partnership with Aspect. Research had to first be carried out to see where the gap lies in the research in order for adults to be adequately supported in terms of their transition to adulthood and further education. The area of transition from adolescence to young adulthood is examined in regards to those who are diagnosed with Asperger Syndrome. This body of work will look to explore the key strategies employed by key workers in Aspect and also interventions used whereby support is given to promote mental health wellbeing. Mental health will also be examined as a substantial amount of research has been performed, examining the link between Autistic Spectrum Disorder (ASD) and mental health issues such as anxiety and depression by Bellini and Tantam which will be explored further on.

1.4 Research Objectives

The following are the research objectives which will guide this piece of research:

- Examine the key strategies and interventions which are used by key workers with clients in Aspect.
- Investigate what is meant by the transition from adolescence to adulthood and why this is particularly difficult for someone with Asperger Syndrome/High Functioning Autism.
- Research social functioning in terms of Autistic Spectrum Disorder.
- Explore the link between Asperger Syndrome and mental health difficulties.
- Explore the issue of furthering education for a client with Autistic Spectrum Disorder and why extra supports are required.

1.5 Conclusion:

The aim of this chapter was to set out the research which is to be conducted in this research project. The research was explained in detail in the introduction. A background to the study was explored and this set out as to why this research project was relevant. The rationale for the study also provided reasoning as to why the research topic was important. To conclude, the aims and objectives of the research project were explored.

1.6 Chapter Outline

Chapter One – Introduction

This chapter introduces the topic of research. It provides the background to the study, the rationale and the research aims and objectives which underpin the project. This chapter also discusses Community- Academic- Research-Link (CARL) and Aspect which the study is in partnership with.

Chapter Two – Literature Review

This chapter discusses ASD in general throughout the literature and also the models of disability which underpin practice surrounding the diagnosis. Mental wellbeing, the transition period and social deficits are also explored in terms of AS.

Chapter Three – Policy Review

Chapter three presents various policies and legislations which have an impact on individuals with AS in Ireland in terms of education, inclusion and equality.

Chapter Four – Methodology

This chapter presents the methodological approach which underpins the study. The approaches used in relation to the collection of qualitative data are outlined as well as any ethical considerations and limitations.

Chapter Five – Findings and Discussions

Chapter five discusses the data collected through primary research conducted with key workers in Aspect. Recurring themes in relation to the findings are identified and discussed in relation to the literature and policy review.

Chapter Six – Conclusions and Recommendations

Chapter six draws conclusions from the data collected though primary research and discusses the themes identified. Recommendations are then made on the basis of the findings.

Chapter Two: Literature Review

2.1 Introduction:

The aim of this chapter is to explore Autistic Spectrum Disorder (ASD) and in particular Asperger Syndrome (AS) in relation to pre-existing literature. The chapter will begin with examining ASD and AS and also the concept of theory of mind which appears copiously throughout the literature in relation to ASD and how it affects individuals with ASD. The history of disability will be explored in relation to the various models of disability and how a diagnosis of Asperger Syndrome was viewed. The period of transition from adolescence into adulthood is one which may be of difficulty, in particular for individuals with Autism who are hoping to move into further education and this chapter will explore why extra supports are needed at this time such as in relation to promoting mental wellbeing. This chapter will conclude with a discussion on the differences between the different sectors of higher education in Ireland.

2.2 Defining Autistic Spectrum Disorder:

Although the term Autistic Spectrum Disorder (ASD) is a relatively new term, there are many accounts throughout history which describe certain characteristics which would now be considered to be on the spectrum. Feinstein describes many accounts from the 18th century onwards where certain behaviours of people would now be attributed to someone diagnosed with ASD. Cases had been recorded of one child in Germany who would run around naked frantically and had an acute sense of smell, yet was insensitive to pungent odours, which is now a characteristic well associated with ASD (Feinstein, 2010). In 1943 and 1944 Leo Kanner and Hans Asperger described children who seemed to be socially inept but were of high intelligence. Asperger (1944), observed that some children had delays in relation to socialisation for instance building friendships. It was also observed that these children struggled with understanding empathy and would take particular interest in one topic or subject. They required added assistance in relation to self-help (Attwood, 2007). These children preferred to play with objects as opposed to interacting with other people. This is some of the earliest mentions of now what has become known as Autistic Spectrum Disorder (Lai, Baron-Cohen and Lombardo, 2014). Since the mid-

twentieth century, many developments have been made in regards to ASD and its diagnosis. Even in the last 30 years, the changes between the definition of 'Infantile Autism' as seen in the Diagnostic and Statistical Manual of Mental Disorders 3rd Edition, DSM-III and the current DSM-V is very much worth examining. According to DSM-V, ASD is a pervasive developmental disorder which changed the way it is now diagnosed. It specifies that symptoms must be of early onset even if they are not diagnosed until later years. Such a publication comes with much criticism as critics have commented that it will now make diagnosing ASD more difficult for those who are of higher functioning, such as those with Asperger Syndrome (Jabr, 2012). However, ASD is now used as an umbrella term and key features are set out to aid early diagnosis which are discussed further on as the triad of impairments. The creation of an umbrella term led to the removal of the term Asperger's Syndrome from the diagnostic manual and has led to some controversy which stems from the debate on the positive and negative contribution of labels such as increased stigmatization yet also improved access to care for those affected (Kite et al,. 2013).

A key difference in relation to ASD and the DSM V was the elimination of subcategories, such as Asperger Syndrome. The diagnosis now falls within the one spectrum. However, in Ireland and the UK practitioners still reference the International Classification of Diseases (ICD-10), which still recognises sub-categories including Asperger Syndrome. Therefore, Asperger Syndrome is still recognised in Ireland as a diagnosis. The term High Functioning Autism is not referenced in either the DSM or the ICD, yet is a term which is recognised by people in relation to individuals who meet the criteria for ASD and fall within a high intelligence quotient (IQ) but do not have a speech impairment (National Disability Authority, 2017). Nevertheless, this term can cause much confusion as it includes a wide range of individuals who differ greatly in relation to the amount of support they require to function in society. A person with an autistic diagnosis may struggle with their emotional intelligence and the social aspect of life and can be seen as having three core difficulties. These are impairments in relation to social interaction, social communication and social imagination (Wing, Gould and Gillberg, 2011). In the 2011 study, the researchers called for the need for the manifestation of these impairments to be researched as it is unknown as to whether they are present at birth and call for further research into the behavioural neurology of the diagnosis.

2.3 Models of Disability:

Ireland's history in relation to people with disabilities, which included those who were on the spectrum, lies in that of segregation and institutionalisation. Those who deviated from the norm were neglected and this was carried out throughout the nineteenth and twentieth century. The twentieth century eventually saw the beginnings of a movement away from institutionalisation (Considine and Dukelow, 2009). Considine and Dukelow (2009) further discussed how a movement which stemmed from the US in the 1960's began to challenge the traditional views on disability and placed independence at the forefront along with creating greater awareness surrounding the past experiences of exclusion by people with disabilities.

The medical model of disability is one which is based on the individual and that the 'problem' at hand lies within the individual. It is based on medical expertise and that all knowledge lies within them in regards to diagnosis and treatment (Quin and Redmond, 2003). All investigation into such a person will be based on treatment in the hopes of 'normalisation', often associated with neurotypicals. The term neurotypical is used in the autism community to label anyone who is not on the spectrum (Bibby, 2012), coined by Atwood in 1998. The medical model can very much be seen in various parts of legislation and policies such as in the Disability Act 2005 where disability is defined 'as a substantial restriction in the capacity of the person'. The social model of disability, in contrast, holds the view that society contributes to the disability as it contributes to exclusion in ways such as not having fair and equal access to resources and facilities. Hence, the concept of disability is seen as a social construct. Unlike the medical model, the responsibility does not rest with one individual, yet it is the 'collective responsibility of society as a whole' (Llewellyn and Hogan, 2000). Therefore, society can be held accountable for not adequately accommodating the needs of the entire society.

Baron-Cohen (2000), has written extensively on the topic of autism and has opened up a discussion on whether Asperger Syndrome should be classified as a disability or are those whom have the diagnosis simply different. The arguments against AS as a disability argue that some of the characteristics typical in individuals with autism are seen in a negative light, however, they should be seen as simply different. This opens up the discussion on neurodiversity which examines the neurological differences between a person with and without AS but does not favour one over the other. Baron-Cohen (2000),

gives the example of a child who prefers to study encyclopaedias rather than play outside with other children. This child may simply be different yet society judges the child's actions as an impairment and disability. One argument for the categorisation of AS as a disability is as a result of the medical conditions associated with it such as epilepsy and therefore individuals may require extra supports. Also, the categorisation of autism as a disability may also be a way of ensuring there are extra provisions in place to support those who do need it and would like to avail of it (Baron-Cohen, 2000).

2.4 Theory of Mind:

The term Theory of Mind is popular in the literature concerning Autism. This term first emerged in 1978 in relation to developmental psychology and is understood to be a core deficit in a person with a diagnosis of ASD (Alic, 2009). It refers to "the ability to recognize and understand thoughts, beliefs, desires, and intentions of other people in order to make sense of their behaviour and predict what they are going to do next" (Attwood, 2007). These 'deficits' may be the underlying cause to the 'social, communicative and imaginative abnormalities that are diagnostic' of autism and theory of mind lies at the forefront of normal development in these areas (Baron-Cohen et al., 1997). This triad of impairments or abnormalities, social interaction, social communication, social imagination, were previously mentioned in the DSM IV. An impairment in social interaction is in reference to a reduced display of pleasure from being around other individuals such as displaying signs like smiling and hugging. Impairments in social communication can be described as the "decreased ability to "converse" non-verbally and verbally with another person" (Wing, Gould and Gillberg, 2011). Moreover, an impairment in social imagination is described as the reduced ability in imagining the consequences of their own or another person's actions (Wing, Gould and Gillberg, 2011).

However, research carried out by Ozonoff (1991), showed that children with AS passed the second–order test in regards to the theory of mind. These tests involve the individual reasoning about another person's thoughts (Baron-Cohen et al., 1997). Yet, further analysis on such tests has seen that they are not complex enough to appropriately examine the theory of mind of an adult with Autism. Although they were more complex than the first-order test, whereby subjects had to understand the thoughts of another person without being explicitly told and instead using evidence and reasoning. It was discussed

in the above article by Baron-Cohen how it was rather absurd to use a test on an adult which was also used on a child of the age of 6 whereby the concept of passing such tests meant that such an adult had the same mental capacity of a 6-year-old. The researcher concluded that these tests did not appropriately examine the theory of mind (Baron-Cohen et al., 1997). Happè (1994), carried out a landmark study to further examine the theory of mind and the results found that those with High Functioning Autism struggled with understanding emotions in accordance with the 'Eyes Test' in comparison to neuro-typical subjects. The test involved the subject examining the eye-region of the face in photographs and deciding between two words, the word which most fittingly described the emotion or feeling. Baron-Cohen's critique is very interesting, however, as it proved the hypothesis to be true, that theory of mind is affected in those with ASD regardless of IQ scores. Yet, it is still not a very complicated examination and although some adults examined in the study 'passed' the test, they still admitted to struggling with simple everyday tasks such as going to the cinema as they would struggle with understanding the characters emotions and thought process. Although a person with HFA has impaired Theory of Mind, the concept is still present and is not to be mistaken for the "absence of empathy" (Attwood, 2007).

2.5 Transition:

The period of time from where a child transitions from adolescence into adulthood is critical. It is a time of much change where great pressures are put on people to become more independent, both socially and financially. Many make the decision to live independently while furthering education. An American study revealed that extensive services are needed to ensure that this difficult transition period is achieved as smoothly as possible (Hendricks and Wehman, 2009). It requires a variety of different supports such as assistance in independent living, the individual being placed at the centre of the transition plan and assisted integration into the community. However, although plans had been put in place, the execution of such plans had fallen short and require more attention in order to ensure this critical period is one of much success for individuals with ASD (Hendricks and Wehman, 2009). This transition can be of particular difficulty for someone who has a diagnosis of AS as they face increasing demands in their social world (Kapp, Gantman, and Laugeson, 2011). Young adults begin to experience a world full of

responsibilities and decision making yet for a young adult with ASD, they may not have the ability to understand how to be their own self-advocate in order to acquire the services they need (Geller & Greenberg, 2010 and Townson et al., 2007). A sense of inadequacy and social isolation can also begin to appear during this period of transition according to Kapp, Gantman and Laugeson (2011), as the young adult feels excluded during social engagements with their peer group. Kapp, Gantman and Laugeson (2011) explored this transition under various different headings such as education, mental health and social relationships. It was found that services in the United States such as a lack of daytime activities, higher education and work, majorly declined after individuals with AS left school and that a large proportion of the responsibility was left on the individuals to acquire strong coping skills in order to appropriately deal with this transition. In 2016, the National Council for Special Education in Ireland commissioned a study where they found that Irish students with ASD were generally supported well in primary and post-primary education (NCSE, 2016). However, this support seems to deteriorate and almost disappear once second-level education has ceased. The study made numerous recommendations in relation to improving supports for children and young people with ASD. The NCSE commented that there was a requirement for better and more meaningful opportunities in further education and training services for adults as they were not available to all. This would require all Governmental Departments co-operating to ensure appropriate opportunities are available to all students with a diagnosis of ASD (NCSE, 2016). The study believes by achieving these recommendations there will be a vast improvement in the lives of those with ASD such as better educational outcomes and improved mental wellbeing. Kapp, Gantman and Laugeson (2011) identified that problems begin to appear in third-level education as the system is a lot less structured. The need for strong coping skills and interventions is intrinsic to making this transition smoother for the individual with ASD. The environment in which education is attained can be over-stimulating and can cause stress for sensory reasons. Colleges and Universities may appear significantly larger and impersonal to an individual with autism which further reiterates their unwillingness to participate as this causes further strain. Anckarsäter et al., (2006) and Soderstrom et al., (2002) discussed that services may exist in third-level education to assist individuals with ASD, yet even accessing such services requires a level of skill many individuals may not exhibit or have developed well enough. These skills which commonly appear underdeveloped are those in relation to self-advocacy and initiative. Therefore as a result of these not being developed enough as a result of resources not available or being

availed of, this continues the existence of social deficits in students with ASD. Suddenly, students are exposed to a new environment. This is only one of the many factors that make the transition more difficult for those with a diagnosis.

2.6 Social Relationships:

Social relationships, whether it be building friendships and connections or romantic relationships are a big part of growing up. Evidence has proven that this can cause major problems for someone with autism, (Travis and Sigman, 1998). Struggles with the theory of mind and the ability to understand what their partner or friends are thinking and feeling can cause the person with ASD to withdraw. Adolescents with ASD can sometimes find themselves in situations where they may feel they are 'set-up' due to the fact they are more vulnerable and gullible (Attwood, 2009). They lack knowledge of boundaries and self-understanding which is vital in building any sort of successful relationship. One characteristic which people with autism commonly show is intense interest and focus on a subject. This focus may be shone on to a relationship and a neurotypical may struggle to understand or reciprocate this intense interest which leads to someone with autism feeling misunderstood and secluded. Kapp, Gantman and Laugeson (2011) discussed that a diagnosis of ASD makes it difficult for an individual to comprehend that 'blurred line' whereby they may be overstepping the boundary when entering into a relationship which may actually become slightly likened to stalking. Stokes, Newton and Kaur (2007) discussed how strategies would most definitely benefit these young adults in developing their skills in terms of social and romantic relationships. They found that participants lagged behind that of their neurotypical counterparts in terms of social relations. Peer support was key in learning how social relationships function and therefore strategies based upon interventions of this kind would be beneficial. Schulman and Scharf (2000) in their research, found that social observation by individuals with ASD and learning from their parents actually had a negative impact on improving their social skills and relationships. Skills which may seem simple and inherent to neurotypicals are conversational skills and understanding social cues, yet individuals with ASD particularly struggle with these (Lewis et al, 2007). Difficulties such as this can further heighten the struggle during this transition into adulthood and developing social relationships appropriately.

2.7 Mental Health:

Mental health and in particular anxiety are extremely common in individuals with a diagnosis of ASD. Reaven (2010) discussed children and adolescents with Asperger Syndrome as being at an even greater risk of showing symptoms of anxiety. Further analysis revealed that these symptoms can be increasingly debilitating for individuals with ASD as they can have a negative impact on the development of social relationships while also affecting their academic performance and 'further exacerbating the core-deficits of ASD" (Sze and Wood, 2007 pg. 256). Bellini (2004) identified that although a small amount of research has been carried out on the correlation between high functioning autism and anxiety, there is still a lack of supports provided to aid those with Autism. Bellini (2004), also examined the correlation between HFA in adolescents and anxiety and social skill deficits and found the results to prove that the adolescents examined in the study did experience anxious tendencies at a greater level than 'members of the general population'. Tantam (2000), found that anxiety was almost universally comorbid with AS. This increased risk and presence of anxiety can further intensify and influence the presence of social phobia. Long-term anxiety can also manifest into depression and Tantam (2000) further highlighted that there is a lack of research carried out on this topic in relation to whether supports such as family can have an effect on decreasing the likelihood of depression. Bellini (2004) also examined the various types of anxiety which are more prevalent among those with a diagnosis of ASD such as social anxiety which was found to have been associated with deficits in social skills. The increased existence of empathy also has an effect on individuals with AS. An individual which exhibits a high level of empathy may also be much more aware of their lack of social skills or that other individuals will see them as socially-inept and this further intensifies their social anxiety. Moreover, Bellini highlights the need for more research to be carried out on empathy and its relationship with ASD. In their study on the period of transition, Kapp, Gantman and Laugeson (2011) made a link between social relationships and mental health and discussed the argument that adolescents and young adults are more likely to show symptoms of depression and anxiety if they feel excluded from social interactions from peers. Depressive symptoms and social anxiety may become more intense during this period, becoming expressed internally in the form of isolation but also externally in the form of aggression (Ghaziuddin et al., 2002). These increasing symptoms reduce motivation in terms of growth as humans and lessen their independence. One recommendation made by

Kapp, Gantman and Laugeson (2011) is increased provision of services to promote mental wellbeing and support self- sufficiency. Also discussed was the importance of gaining knowledge in relation to ASD, which will increase the availability of support and the creation of intervention strategies which would be aimed towards creating the possibility of 'achieving greater success' for individuals with HFA.

2.8 Disparities between different sectors of education:

In relation to third-level and further education in Ireland, there are clear disparities to be seen in relation to the level of funding given, resources allocated and delivery of service. Since the period of extreme austerity which occurred from 2008 onwards, the education system has seen cuts of €200 million (Ni Aodha, 2016). However, it is not merely Universities and Institute of Technologies which have been affected. Colleges of Further Education have been impacted dramatically as they rely completely on Government funding. The term 'Cinderella Sector', is often associated with the Further Education sector although they provide over 22,000 courses (Ni Aodha, 2016). This sector provides both a range of courses which suit the needs of many thousands of students while also being a stepping stone for more into Higher Education courses. As discussed, students with Asperger Syndrome do in many instances require extra support as they transition to third-level or further education (Barnhill, 2014). However, due to the high levels of inadequate funding in colleges of Further Education in Ireland, it is evident that these extra supports will be difficult to fund, leaving many students feeling inadequately supported. Colleges of Further Education offer students the opportunity to experience courses or a particular field of interest prior to them committing to a third-level degree. This can offer a smoother transition to experience and achieve independent study (Ni Aodha, 2016).

2.9 Conclusion:

This chapter has examined the relevant literature surrounding Autistic Spectrum Disorder. It has analysed the discussion in regards to a diagnosis of ASD as it is currently recognised, specifically focusing on Asperger Syndrome and whether it should be classified as a disability. This chapter highlighted the struggles individuals with ASD face such as in

regards to mental health and social relationships. The period of transition into further education was explored in relation to the inadequacy of supports and provisions. The chapter concluded with an examination of the link between ASD and mental health and how mental wellbeing has an impact on many other aspects in an individual's life and the various disparities in the various sectors of higher education.

Chapter Three: Policy Review

3.1 Introduction:

This purpose of this chapter is to analyse social policy from the Irish perspective in terms of education, equality and inclusion for individuals with a disability and specifically ASD. This section will begin with an exploration of the background of disability in Ireland. Various reports and commissions will be examined in relation to education, inclusion and human rights for those with disabilities and in particular those with a diagnosis of Asperger Syndrome. The chapter will conclude with looking towards the future in terms of the National Access plan and proposed Autism Bill 2017.

3.2 Context and Background to Disability:

In Ireland in the 19th and 20th centuries, attitudes towards individuals with disabilities were shrouded in misunderstanding and a lack of knowledge which therefore led to neglect, segregation and institutionalisation (Considine and Dukelow, 2009). Considine and Dukelow (2009), further discussed how the middle of the twentieth century saw a move towards human rights and the growth of the belief in individuals with disabilities that were entitled to rights. The origins of the disability movement emerged from the US in the 1960's and 70's (McDonagh, 2012). It took two decades for Europe and Ireland to follow in the footsteps of America and challenge the attitudes and provision of services and support for individuals with disabilities (McDonagh, 2012). The medical model contrasts with the social model of disability as explored previously. In the past there had been a lack of recognition for the need to provide adequate supports and services for those with disabilities. In the 1960's numerous reports were published in relation to education provision, yet they lacked the challenge of segregation which was a major problem and also they did not address post-primary education. The medical model of disability also stood in its dominant position.

3.3 Report of the Commission on the Status of People with Disabilities (1996)

Until the 1980's, policies in relation to disability were seen as the responsibility of the Department of Health. Services in relation to employment, education or independent

living were all dealt with in the one department (Quin and Redmond, 2003). However, the 1990's as described by Considine and Dukelow (2009) was a real turning point in relation to policies and practices with such reports as 'A Strategy for Equality' (1996) having been published. The attitudes of the Irish population began to be steered towards a more social model of disability. Irish citizens became infuriated by the treatment of individuals with disabilities. Official documents such as the 1996 Census neglected disabilities and segregated them from society. One major area of concern identified in the report was in relation to education (Doyle, 2003). Adequate education was not being provided and this was having a detrimental effect on employment opportunities as well as training in comparison to the percentage of the population without a disability. A lack of equality was clearly evident. The commission began to review the conditions which were a necessity to allow individuals with disabilities to participate fully in socio-economic and cultural life (Doyle. 2003). 'A Strategy for Equality' made many comments and recommendations in terms of education. It discussed the gap between mainstream education and special schools and that this gap should be lessened in order to allow students to become more flexible and have the opportunity to move more freely between the two. The report also mentioned the need for more supports to be acquirable for those with disabilities in relation to education. However, it does not go into detail about any specific level of education and fails to mention third-level throughout. This report also only discussed disability in general and does not mention Autistic Spectrum Disorder specifically or any other category of disability. The main aim and success of this report was that is started the discussion on disability and ensured that it stayed at the forefront of the agenda (A strategy for equality, 1996).

The Commission was also responsible for the establishment of the National Disability Authority (NDA) as a statutory agency in 2000.

3.4 Education Act 1998:

As mentioned previously, the 1990's in Ireland was a turning point in Irish legislation for the recognition that citizens with disabilities had been neglected in the past and there was a greater need for equality in the future (Considine and Dukelow, 2009). The Education Act of 1998 'provides a statutory basis for policy and practice in relation to all education provision (Griffin and Shevlin, 2007). The definition of disability as seen in the Act is one

which would be categorised under the medical model of disability seeming as it 'located the source of educational difficulties within the child' (Griffin and Shevlin, 2007), and ignores any external factors. An individual with autism is impacted greatly by external environments and so is in conflict with the definition of disability provided in the act. The Act is worthy of examination as it was the first time there was a statutory framework for the education system in Ireland, however, it only included first and second-level and fails to provide policies to support those who wish to engage in third-level education to an extensive level (Government of Ireland, 1998).

3.5 National Disability Authority:

The National Disability Authority (NDA) has published reports in recent years in relation to autism and services available in Ireland.

The National Disability Authority released a report in 2015 titled 'Reasonable Accommodations for people with Autism Spectrum Disorder'. The report focused on education, however, mentioned very little in regards to third-level education and in particular the difficult transition which is experienced by a substantial amount of young adults with autism (National Disability Authority, 2015). The report focused more on the transition experienced by children moving to different schools. There is only a brief mention of aiding this transition in regards to developing Individual Education Plans. It does not analyse in-depth this critical period and which additional supports are available in Ireland at that particular period of time.

In 2017, the Authority published 'Models of good practice in effectively supporting the needs of adults with autism, without a concurrent intellectual disability, living in the community 2017'. The report acknowledged the growing number of individuals with autism in the Irish education system who require a wide range of services and provisions. However, the report identified a deficit in the Irish system whereby there are no clear supports for adults with ASD who attended third-level education and felt the need to drop out due to not being able to cope. There is no clear guide which shows whether autism services are available, and where they do exist, there is little assessment of how well they work. The report highlighted that the period of transition for a student with autism to third-level education is key and can be a turbulent and difficult time. This transition period can be a time where individuals diagnosed can find it difficult to access social care services

and therefore this intensifies feelings of isolation. The transition generates a loss of structure and also a limited supply of services being available in relation to adults and education (National Disability Authority, 2017). The Authority discussed that colleges have a responsibility in ensuring they are tailoring specific supports to the needs of those with Autism. Trinity College Dublin has had an increase in the number of students with autism enrolling in recent years as they have improved their supports in relation to entering college and what to expect and utilising skills learned throughout their college years. They have used supports from both the disability and occupational therapy service whereby a model of support was developed to aid students with ASD as they continue with their college education. The report draws on information from the UK and *'A College Inclusion Charter*' which has the aim of supporting students with autism adequately by providing services which aid the transition process and identified inclusion as key. A few examples of good practice included in the charter were to designate a "meeting and greeting" area at the college reception, to have staff trained specifically to help the needs of those with ASD, and support in the area of organisation. The colleges in the UK which participated saw many positive results such as increased enrolment of students with disabilities and students who were reported to appear happier as they became more involved in the community and made positive contributions which aided their personal and social development. The report also highlights the need for more research in terms of identifying which key strategies and interventions are best suited for those with ASD and no intellectual disability. The NDA report concluded that there is a substantial gap in the services which currently exist in the Irish system for individuals with ASD non-ID as there is little research haven been undertaken on this group of individuals and it suggests that the Health Service Executive (HSE) and service providers and stakeholders meet in order to discuss the next steps in regards to the findings of the report.

3.6 Education for Persons with Special Educational Needs (EPSEN) Act 2004:

This act provided a much wider definition of special educational needs than in previous acts above and the definition of disability is from a social model of disability perspective. The act saw much improvement in terms of promoting greater equality in education which saw a substantial investment in more special needs assistants. The act also saw the establishment of the National Council for Special Education (NCSE). The council has a significant role in ensuring special education needs are met and they also play a role in

assisting the Minister in advising him on matters related to special education. The act was based on inclusion and equality and making the education system a place of equal opportunities. Inclusion was no longer to be a concept which was hoped for in the education system, instead, it was mandatory and expected (Griffin and Shevlin, 2007). However, this proved to be difficult as a significant amount of responsibility was placed on each individual teacher in schools and principals to ensure their students received an adequate standard of education. Yet, as a result of a major lack of experience on the part of many mainstream school systems in Ireland, many of the goals and aims of the act fell through without being fully implemented. One goal of the EPSEN act was for individual Education Plans (IEP) to be implemented. The introduction of IEPs was also aimed at aiding the transition period for students with special education needs as they progress to becoming an adult in terms of receiving an adequate level of education or training. The purpose of such plans was to ensure each student has the opportunity to have their own specific learning needs examined and catered to. However, as with many parts of the EPSEN act, the proposal for IEPs also fell through due to economic constraints and have yet to be fully implemented in accordance with the legislation (EPSEN, 2004).

3.7 Disability Act 2005:

The Disability Act 2005, commissioned by the Department of Justice, Equality and Law Reform had the aim of expanding social inclusion. The Act built on existing policies and legislation such as the EPSEN Act and the Equal Status Act 2000. It promised to make significant and long-term improvements to the lives of individuals in Ireland with disabilities. One of the most significant promises the act made was the appointment of Individual Assessment of Need plans in terms of health and education for those over the age of 18. However as discussed by Dukelow and Considine (2017), this part of the act still remains unimplemented. The assessment which was intended for all adults over the age of 18, is in reality only available to children born after 2002. Also, a little over half of the assessments made in 2015 were completed and the time it took for them to be completed exceeded the six-month time frame which was specified in the original act.

3.8 National Disability Inclusion Strategy 2017-2021:

In 2017, the Department of Justice and Equality launched a strategy which is due to run for the next five years. It succeeds the National Disability Strategy of 2004-2015. This previous Acts failure, combined with a history of failure in terms of disability policies and legislation means that the strategy proposed for in 2017-2021 has to make and live up to a lot of promises (Dukelow and Considine, 2017). The strategy makes it clear that there is a governmental understanding that the problems individuals with disabilities experience in terms of inclusion and equality go far beyond merely education. However, education is still regarded as one of the eight themes which need vast improvements. One of the opening actions which the strategy sets out is the overcoming of obstacles in order to allow the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Ireland only recently ratified the Convention in March 2018. It sets out targets for nations to achieve in order 'to change attitudes and approaches to persons with disabilities' (Un.org, 2018). The United Nations (UN) is seeking to work towards a world where disability is no longer seen as charity and instead that they are entitled to rights along with every other human being so long as they have the capacity to claim their rights. In order to ratify the convention, certain laws and legislation would have to change which is why the process has been much delayed in Ireland. Autism-Europe is an organisation which aims to advance the rights of individuals with ASD and their families and also improve their quality of life (Autism-Europe, 2016). They have advocated for the adoption of the UNCRPD by European Union (EU) member states. The ratification of the convention has meant that de-institutionalisation has begun to take place with evidence of inclusion becoming more of a reality for children in mainstream settings in terms of education (Autism-Europe, 2016). Article 24 of the convention discusses the development of inclusive education systems at every level. This is a legal obligation for all member states who ratify the convention (Ramaahlo, Tönsing and Bornman, 2018**).**

In regards to the National Disability Inclusion Strategy and education, there are twelve actions it aims to adhere to. The strategy mentions ASD in particular where it aims to develop implementation plans for policy advice on autism for the NCSE to carry out. It also mentions third-level education in particular and addresses the need for the continuation of education to be promoted among individuals with disabilities (National Disability Inclusion Strategy 2017-2021). However, once again this is the only mention of third-level education and it is a very general statement and fails to go into detail of how

it is exactly going to go about promoting the attendance of higher education for those with a disability and this highlights how yet again this is much overlooked in Irish society.

3.9 National Plan for Equity of Access to Higher Education 2015-2019:

This National Access Plan which consists of five key goals has the intention of assisting under-represented groups in society to participate in third-level education. One under-represented group which the plan highlights are students with disabilities. The plan is underpinned by the principle that everyone should have the opportunity to participate in third-level /further education and that those who do should be representative of all the population, regardless of disability for example (National Plan for Equity of Access to Higher Education 2015-2019, 2015). The plan increased funding for students with disabilities, with the intention of ensuring necessary resources and supports are available for all.

3.10 Autism Spectrum Disorder Bill 2017:

In 2017, the Seanad passed the bill which calls for improved supports for individuals with autism. The proposed bill, if enacted, will be the first of its kind in Irish history and follows the footsteps of many other countries such as England and Canada. The bill states that it will be the responsibility of the Minister for Health to publish an 'Autism Spectrum Disorder Strategy' (Autism Spectrum Disorder Bill, 2017). This strategy will discuss the various needs individuals with ASD may have throughout their lives and how they are to be addressed and catered for. It will set aside a system whereby services and facilities currently available to assist those with autism can be reviewed to assess their success. The strategy is to be published no later than two years after the passing of the Act and it should be under review periodically. The strategy covers a wide range of services and service providers, for example, in terms of education, healthcare and employment. The strategy also sets out to aid and support the needs of the family and those who are supporting the individual with autism can also be supported. The strategy also places an emphasis on equality of services and ensuring that each individual should have an equal opportunity to access a range of services which are available throughout the state. The proposed bill also sees that defining a 'best model of service delivery, assessment, diagnosis and intervention' for an individual with ASD is very important. The entire responsibility rests

with the Minister for Health in order to implement the strategy but also required a multi-disciplinary approach between all departments. The strategy fails to mention the critical transition period for an individual with ASD if they choose to go down the path of further education. The strategy also does not mention bridging the gap between services for people with ASD. It is unknown as of yet whether this strategy will ever be fully implemented and if so, how successful it will be as it promised and guarantees a lot.

3.11 Dare Scheme:

In Ireland, there currently exists the Disability Access Route to Education (DARE) which aids students who wish to attend third-level education and their disabilities have impacted their second-level education negatively (Accesscollege.ie, 2018). This scheme encourages the participation of students into colleges and universities from all walks of life. The scheme aims to ensure that third-level education in Ireland is a diverse place that is representative of the society with surrounds it. The DARE scheme assists students who may wish to further their education, yet may not have achieved high enough points for their desired course. Eligibility for the scheme falls under many categories with Autistic Spectrum Disorder being one of them. The introduction of such a scheme is due to research proving that a student with a disability such as ASD from a disadvantaged background may face great difficulties when it comes to progression to higher education (Accesscollege.ie, 2018).

3.12 Conclusion:

This chapter has examined various policy legislation in the Irish context in relation to disability and inclusive education. The chapter has examined the changing view on disability in terms of models of disability and how this has an effect on how disability is viewed by the population and in turn inequalities may arise. The chapter outlined that the 1990's was a turning point in terms of legislation for individuals with disabilities and from there on many legislations began to change. However, individuals with disabilities and in particular autism seem to have been forgotten about and lack the adequate policies in order to feel equal in Irish society. This chapter concluded with an examination of the proposed Autism Bill 2017 which proposes to achieve greater equality and inclusion for individuals with ASD.

Chapter Four: Methodology

4.1 Introduction:

The aim of this chapter is to discuss the various theories and approaches which have informed this research project. The chapter will also explore the methods which were employed in the study throughout the data collection and analysis process. Subsequently, the various ethical considerations and limitations will be analysed which had an impact on the study.

4.2 Community-Based Research:

This piece of research was conducted in collaboration with Community-Academic Research Link (CARL) and therefore has been informed by Participatory Action Research (PAR). Community-based research (CBR) is whereby a student collaborates with a community partner after a CSO has identified a research question which address a local and/or societal issue (Bates and Burns, 2012). This piece of research differs from many others as it is based upon seeking a greater understanding of the social world and improving it by making changes to it. It also contrasts with other pieces of research as it is 'completed "with" others rather than "on" or "to" others' (Creswell, 2007). It is distinctive as it has a central focus on conducting research which will aim to make a difference (Baum, MacDougall and Smith, 2006). The researcher works through a reflective cycle whereby the data collected and analysed informs what actions need to be taken. Baum, MacDougall and Smith (2006) further reiterate that power relations are intrinsic to PAR so as to ensure power is shared between the researcher and those being researched as they work in collaboration to create the research topic and carry on working in partnership throughout the process. Strand et al (2003) described CBR as having its goal situated in achieving social justice. A CBR project requires a specific focus early on in order to facilitate equal discussions between all partners (Bates and Burns, 2012). This approach can be described as dialectical or recursive as its central focus is on bringing about change. This is, therefore, the reasoning as to why the researcher shall aim to advance changes after said piece of research is conducted. (Creswell, 2007).

4.3 Theoretical Perspective:

This collaborative piece of research is also informed by interpretivism. This is whereby the issue is in relation to the nature of reality and its characteristics (Creswell, 2007). Creswell (2007), continues to describe this approach as seeking to view reality as subjective, seen from the perspective of the study's participants. Ritchie et al. (2014) discussed qualitative data as having placed an emphasis on human interpretations of the social world and that both the researcher and participants are equally significant. The concept known as *verstehen* is intrinsic to interpretivism and can be described as understanding, whereby the researcher arrives at an 'interpretation of human action' (Schwandt, 1994). Ritchie et al (2014), described interpretive qualitative data as having placed a strong emphasis on human interpretations of the social world and that there is both a prominence to be placed on both the participants and also the researcher's understanding of the concepts and data being explored and studied.

4.4 Methods:

In this research project, the researcher chose to use qualitative measures as the method of collecting primary data. Primary research is collected specifically for the research at hand and generates new data to add to that which previously exists (Hox and Boeije, 2005). This study was conducted in collaboration with Aspect. Qualitative research methods developed out of the need for an increased understanding that was required for specific concerns in relation to social policy (Rich. 1977). For the purpose of this research, the researcher chose to conduct five face-to-face, 10-20 minute interviews with key workers in Aspect. The reason for this number of interviews is due to the fact that all the key workers which are interviewed are each from the same organisation, Aspect and so many will have similar opinions and points of view and may give similar responses. Creswell (2013) identified nine key characteristics of qualitative research. The first characteristic identified was that the data is often collected in the natural setting, this is whereby the research gathers their information by talking directly to participants in a setting where the action discussed takes place. In this method, it was also identified that the researcher is a key instrument in data collection, whereby they conduct the data collection themselves. They often collect the data by their own means such as the use of formulating open-ended

questions instead of relying on other forms of data collections created by other researchers, for example, questionnaires (Creswell, 2013).

4.5 Sampling:

This study utilised criterion sampling and a purposive sampling strategy (Creswell, 2013). There are three considerations to be explored in this strategy. These include the decisions to be made by the researcher as to who are going to be the participants in the study, what specific type of sampling strategy will be utilised and what size the study sample will be (Creswell, 2013). It was used due to the fact that each participant had a particular characteristic which would enable the researcher to explore the central themes and questions highlighted in the study (Bryman, 2012). In a phenomenological study such as this, participants are chosen on the basis of having experienced such a phenomenon. The participants were selected and asked permission if they would be willing to take part in a study by the researcher with the aid of the liaison officer in Aspect. The researcher met with the liaison officer and discussed the ideas for the research questions. The liaison officer then assisted by making contact with a number of key workers within the organisation that they felt would aid the study by giving an accurate representation of the work conducted within. Five key workers were chosen with diverse professional backgrounds. The liaison officer in Aspect was of incredible aid and assistance to the researcher as without this link person, it would have been difficult for the researcher to have made contacted with the participants and ask for their participation. This strategy for sampling may be seen as a limitation as it was not a random selection, however, it was intrinsic to the study that each participant was handpicked so as to ensure that the data collected would be as rich in information as possible.

Five participants were chosen so as to allow the researcher to be able to have the appropriate time to analyse the data collected in depth and identify key themes that may emerge through the interviews. The data collection setting was chosen by the researcher in accordance with the liaison officer as the organisation collaborated with the student and expressed that they would have a meeting room available to use when the time arrived for the researcher to carry out the interviews.

4.6 Data Collection Approach:

For this particular research project, the researcher chose to collect primary data in the form of semi-structured, one-to-one interviews consisting of a series of open-ended questions. A semi-structured interview is one which the interviewer has a general set of questions but is able to slightly vary the sequence of questioning for each interviewee. The interviewer is also able to change some questions throughout the interview in response to some of the answers received (Bryman, 2012). One disadvantage of a one-to-one interview is that a lot of pressure is put upon the interviewee as they are solely relied on to provide rich data for the interviewer to use (Creswell, 2013), as opposed to a focus group where participants can rely on each other to generate discussions and ideas. It is difficult for the interviewer to know whether the participant is the correct one which will not be hesitant or shy and in this research project, the researcher had no way of knowing whether the participants would provide adequate data to analyse as there was no previous relationship between the interviewer and interviewee. Silverman (2004), described emotionalists as viewing open-ended interviews as eliciting "authentic accounts of subjective experience".

The process of forming questions for the semi-structured interviews was one that is unique to the Participatory Action Research (PAR) approach employed in the research. The researcher constructed the interview questions with the aid of the liaison officer in Aspect as they informed the researcher what kind of data and feedback they were seeking. With this, the researcher then constructed seven interview questions which were broken down into two categories. Firstly, questions related to the work Aspect conduct in relation to promoting mental wellbeing with their clients during the transition. Secondly, the researcher also constructed questions in relation to supports in third-level/further education which currently exist and may need improvement.

One very important element of a one-to-one interview is for it to take place in a suitable setting where both the interviewer and participant will both feel comfortable. The interviews took place in a setting which was set up with the aid of the liaison officer. For recording purposes, it was also important for the interview to be conducted in a quiet area where there would be no interruptions (Creswell, 2013). It was imperative to the study to have an adequate recording device such as a Dictaphone. The researcher chose to record the interview on their mobile phone which was password protected as this was the only recording device available to them at the time of the scheduled interviews. For data

confidentiality purposes after the interviews took place, all audio data recorded was transferred to a password encrypted computer and all audio files were deleted from said mobile phone. Kvale and Brinkmann (2009), highlighted the vitality of having an interview protocol or guide which is a sheet of paper with the interviewer's questions on it and also space to take some notes and record key information from each interview.

4.7 Data Analysis:

The researcher used a thematic approach as the method of data analysis. After the researcher conducted the interviews which they had recorded via a Dictaphone, the researcher transcribed one interview in full, verbatim which they felt provided the most relevant and data-rich information. The researcher also transcribed detailed notes from each of the remaining four interviews. The participant's names were not recorded and instead, each interviewee was assigned a number. The researcher then analysed the transcripts and identified reoccurring themes from each interview and this data was grouped together. Creswell (2013 p.186), identifies themes as 'broad units of information that consist of several codes aggregated to form a common idea'. The researcher engaged in interpreting the data. This involves a process which begins with the development of codes, forming themes and then broadly organising the themes so that the researcher can make sense of the data collected (Creswell, 2013). The researcher used quotations from the interviews to highlight the themes which emerged. The research then reviewed the literature review previously conducted in order to compare the new data collected with which that had previously existed.

4.8 Ethical Considerations:

The research undertaken in this research project involved the collection of primary data and therefore involves ethical consideration. Ethical issues arise in all types of social research, however, they are specifically relevant in qualitative data as this type of data often 'intrudes more' in participant's lives (Punch, 2011, pp. 276). Firstly, the researcher with the aid of their supervisor completed the ethics form from the Social Research Ethics Committee (SREC). The researcher's supervisor approved the form after a small number of recommendations were made. Creswell (2013) highlighted that ethical issues may arise

at any time throughout the research project. It was also highlighted during the research process that although anonymity of the participants in the interviews was to be kept confidential, all the participants were from the same organisation and there would be a chance that participants may know each other and may have discussed the study between themselves. Punch (2011), had discussed this as being intrinsic to the ethical issues which may arise while conducting primary research. The researcher guaranteed to keep all participants information anonymous and although the organisation is referred to in the research project, no participant would be identifiable by name.

Ritchie et al (2014) discussed how the issue of ethics at times may come in conflict with the researcher attempting to conduct adequate quality research. The writer elaborated on how it would be uncommon and wrong for a researcher to purposely conduct research unethically by perhaps coercing participants into taking part or asking questions which are intrusive purposely. However, this may happen when the researcher is attempting to get the most out of the research. During the research process where the researcher was drafting question to ask participants, the interviewer had to re-draft the questions as when the researcher consulted with the liaison officer, they felt one question, in particular, was too intrusive and unnecessary. This once again highlights the collaborative process involved in a CARL project and also the importance of ethical considerations.

Each participant prior to taking part in the study was sent an email of invitation, an information sheet and consent form to review. The email of invitation explained to the participant the purpose of the study. The information sheet described what the study involved and why the participant had been invited to take part. The form also informed the interviewee how their participation was completely voluntary and assured them that all data collected would be kept secure and their identity would remain anonymous. The form outlined how data was to be collected and stored. The researcher also provided contact details if any participant had any questions about the study. These information forms and consent forms were given to the participants via the liaison officer at Aspect. On the day of the interviews, prior to the interviews taking place, the researcher met each of the interviewees and gave a short synopsis of the research undertaken and offered the opportunity to ask any questions they may have had. Once this was completed, the researcher issued each participant with a consent form and each participant signed.

4.9 Limitations:

One potential limitation of this study was that all the primary research which was collected was from participants all working in the same organisation which may have had a bias towards the work they were doing. As the researcher only had a limited amount of time to conduct this small-scale research project, the researcher would have preferred to also have had the opportunity to interview more participants outside of the one organisation who work with individuals with ASD who are in the transition process. As the participant all came from Aspect, there was also a lot of overlap in the data collected.

A further limitation of this study was that the researcher did not have the opportunity to conduct the interviews separately which is usually typical of a semi-structured interview. Subsequently, all interviews were conducted in one two-hour slot as that was the only time where all key workers were available and therefore the interviewer did not have the opportunity to trial the questions to gauge whether they were adequate to receive data as rich in information as possible.

4.10 Conclusion:

The purpose of this chapter was to investigate in depth the qualitative data collected in this research project. The chapter examined the various theoretical approaches used in the research and how the collaborative process with CARL was intrinsic to the quality of data collected. The researcher also discussed how the data was collected and analysed. Finally, the researcher examined the various ethical considerations which arose during the process and the various limitations which arose with this.

Chapter Five: Findings and Discussions

5.1 Introduction

The purpose of this chapter is to explore the findings of the qualitative data which was gathered by the researcher as they conducted five face-to-face interviews with key workers in Aspect. The researcher undertook thematic analysis on the data collected and then divided them into various themes which were:

1) Transition Period
2) Social Skills Deficit
3) Strategies used by key workers
4) Existing Student Supports

The data collected represents the views of key workers in Aspect. In relation to the theoretical perspective used during this research project, the research applied an interpretivist approach when analysing the interviewee's responses. The researcher employed the use of quotes to emphasise the thoughts and opinions of the key workers on the subject discussed.

5.2 Transition Period:

Throughout the course of interviews, all participants acknowledged that as a result of the organisation being client-centred, each client required varying levels of assistance and it very much depended on the individual. Each key workers in Aspect acknowledged that the transition period can be a difficult time yet there is a proportion of their clients which do report as having managed the transition period themselves and thrived as independent individuals.

> R3: "*A lot of people I work with…have managed the transition really well themselves, they have kind of used the extra independence to kind of grow as a person and to….take control of their own independence and learning a bit more".*

In each interview it was stressed how the level of support and assistance needed by each client was very much individual, further emphasising that the work carried out in Aspect is very much client-based.

> R2: *"I do think our client base need quite a bit of support, now obviously its individual, what one client is going to need in regards to support as opposed to another is very very different"*.

However, it was also noted by the key workers in Aspect that this transition period experienced by their clients as they become an adult and also move into further education, is a critical point which is worth examination due to the sheer fact that it can have the potential to cause their clients to struggle and require additional support.

> R1: "*What happens if people don't get support is that they fall through the cracks in the system*".

> R2: *"By the nature of having Asperger's, I suppose change is a massive thing for our client base... change in routine, changes in faces, not being able to access adequate support…what could make or break having a successful time in college"*.

The transition period was discussed in relation to the differences experienced by individuals with Asperger Syndrome and why it is a particularly difficult period of time for individuals with a diagnosis

> R3: *"The reason they do need it [additional support] when transitioning from second-level to college is because of the huge difference"*.

> R5: *"Being a spectrum condition... the challenges that present with Autism can manifest in a lot of different ways"*. .

The difference between second-level and third/further education was emphasised copiously throughout the collection of primary data. Second-level was described as being more focused and support easier to access whereas there is a distinct increase in the level of independence expected for clients with Asperger Syndrome which may result in them struggling during this period. One key worker, in particular, described the difference between the different levels of education and the experiences of clients with AS.

R1: *"They can do quite well in second-level because it's a very kind of rigid.. prescribed… there is someone standing over them, kind of spoon-feeding them...it's a very structured environment which can be very suitable for people on the spectrum".*

R2: *"In secondary school…they may have had a SNA…it's an extraordinarily structured environment… the expectation of college is vastly different…it's a far far looser environment".*

R5: *"In the bigger colleges… it's very easy to get lost and become anonymous… in the Colleges of Further Education… they are smaller and more intimate so it's more challenging but that can bring its own pressure... a sense of expectation".*

5.2.1 Transition and Mental Wellbeing

As the transition period was discussed by each participant in relation to the effects it has on their clients with a diagnosis of Asperger Syndrome, it became apparent that one of the main aspects of their client's lives which was impacted both positively and negatively was their mental wellbeing. One interviewee discussed their experiences of having had clients who were struggling prior to the transition period and these feelings of isolation and social challenges further developed throughout the transition.

> R5: *"Low self-esteem, negative self-image...can tend to develop unhelpful coping strategies…unhelpful habits…that sort of thinking can manifest into everyday life where they come to see everything as a threat".*

This particular respondent also emphasised that a proportion of the clients in Aspect self-reported as having enjoyed the transition from second-level education, having used the opportunity to make new friends and had the ability to choose what area of interest they would like to study.

R5: "*Impacted positively if they are able to form new peer groups, new relationships and maybe study something they really enjoy"*

Routine was a reoccurring theme throughout many interviews as having had a huge impact on mental wellbeing. It was highlighted in the disparities between different levels of education that there was a loss of routine experienced by many clients of Aspect as they transitioned to further education.

R1: *"For anyone quite attached to their routines and not very adaptable, this change can be extremely stressful"*

5.2.2 Earlier Transition:

Many respondents commented that they felt there was a lack of coordination between adult and child services which meant that adult services do not have contact with a client until they are eighteen and may have already begun the transition period and feel a lack of support. To combat such an issue, many key workers discussed the idea of beginning the transition process earlier to give their clients the best possible chance of success.

R2: "*The transition period should start earlier…forecasting that the transition period is coming up and preparing for it well ahead of time".*

In accordance with this opinion, the key worker suggested that the transition period could even be introduced as early as transition year in school, approximately at the age of sixteen so as to ensure students can be well equipped with the necessary skills they may need in the future.

R2: *"Maybe looking on from transition year onwards…maybe induction programmes...open days for people with AS".*

Another key worker also mentioned once again that Aspect's client base only get to meet their key workers by the time they have already reached adulthood or began college and they would find it beneficial if there was some way of lessening the gap between child and adult services.

R1: *"It would be very helpful if child services were involved in the transition…between us we could handle that really important preparation…A, going from child services to adult services and B, going from second-level to third-level…it's two really important transitions".*

5.2.3 Discussion

From conducting interviews, it became apparent that similar themes which have been relevant throughout the literature explored began to emerge. Each participant was asked

directly about the transition period experienced by individuals with AS and why they felt their client's mental wellbeing may be impacted during this time. Some participants acknowledged the difficulty this transition period can bring but it can be managed properly and explored as a period of growth and independence. This was a concept which had not appeared in the literature examined and much of the focus had been on the negative connotations in relation to this time. Almost every participant viewed the transition as very much an individualised experience which re-emphasised the importance of Aspect's work being client centred. This had been explored by Wing, Gould and Gillberg, (2011) in their discussion on the diagnosis being associated with a triad of impairments. Kapp, Gantman and Laugeson (2011) had discussed in the literature the growing demands of a social world which can be a source of stress and difficulty which was highlighted once again in the primary research conducted. Kapp, Gantman and Laugeson (2011) examined the less structured environment which is common in third-level and further education institutes which can cause stress and a calling for increased resources in relation to students exemplifying stronger coping skills. Another theme which was explored in the discussion with the participants in the interviews was their opinions on beginning the transition period earlier. Many participants spoke of the lack of coordination between child and adult services in Ireland. They discussed their opinions on beginning the transition into college or further education earlier which would allow for the maximum amount of preparation which would also for the greatest chances of success in relation to the transition. This theme does not correspond to the literature or relevant policies as the proposed Autism Bill fails to mention the gap which lies in the services and also does not pay particular attention to the transition period. Although the literature acknowledges the difficult period, it does not suggest beginning it earlier so as to assist the individual with AS (Kapp, Gantman and Laugeson, 2011).

5.3 Social Skill Deficits:

A reoccurring theme which was mentioned by the key workers in Aspect was that they recognise a clear deficit in relation to social skills. This is due to the triad of impairments which is associated with Asperger Syndrome. As a result of this, clients in Aspect are accessing additional support to assist themselves where they may feel they are lacking the appropriate skills to enable a smoother transition into further education.

R5: *"When maybe there is a clear skills deficit in a certain domain".*

Many of the respondents explored themes and deficits by naming them in particular such as deficits in social imagination. A strategy which was employed by key workers very often was to aid their clients with social imagination deficits.

R5: *"Sometimes it's just about presenting facts to a person.. if somebody is in college and they are not submitting the work, is that because of social imagination like do they not see the consequence".*

During the same interview, the concept of theory of mind was also introduced as a concept in which many individuals with Asperger Syndrome find themselves struggling within particular as they enter into the transitioning period.

R5: *"It could be those theory of mind issues… when it comes to personal relationships, just role-playing… what the other person is thinking… maybe it's just about exploring expressive body language".*

The idea of social norms was also explored in another interview as being an element which might appear as common sense, yet for individuals with Asperger Syndrome, it may be simple aspects which they might struggle with and affect them more than it would affect a neuro-typical.

5.3.1 Discussion

Another common theme which was discussed in both the literature and the interviews was the discussion on the significant social skill deficits which are experienced by individuals with a diagnosis of AS. As mentioned previously, Wing, Gould and Gillberg (2011) had discussed the triad of impairments associated with the diagnosis. The concept of theory of mind was also introduced into the literature with a definition provided by Attwood (2007) and the exploration of the concept as being one which can further emphasise the difficulties experienced by individuals and the triad of impairments. Much of the literature focused on the diagnosis of such impairments (Baron-Cohen et al., 1997), yet failed to mention as to whether there are services available to aid individuals with them. As a result, the information collected from the participants re-emphasised the importance of such issues as each of these factors does indeed go on to effect a person with AS's perception

of social norms. Attwood (2009) had discussed the centrality of issues such as boundaries which can be related back to the information gathered from key workers where they spoke of their client's struggles with personal relationships and.

5.4 Strategies used by key workers

The interviewer asked directly to each participant which strategies and intervention they used with their clients to aid them with the struggles experienced during the critical transition period. Although again each interviewee stressed the fact that the service provided by Aspect is very much person-centred and individualised, there were also some strategies which were commonly used on many clients which aided them with any social deficits they were experiencing during the transition.

R5: *"It depends…on my day-to-day job, depends on the person"*.

5.4.1 Organisation and Practical Skills

Many of the keyworkers discussed the strategies they felt were of most benefit and also the interventions which were most commonly used. Strategies regarding organisation and planning were mentioned extensively throughout the interview process. Many key workers stressed the fact that it is the skills which may seem simple for neurotypicals, but are difficult for individuals with AS to comprehend.

R1: *"From an organisational, planning point of view…becoming well acquainted with the campus…going to the campus a number of times...getting to know all the different buildings"*.

The key worker highlighted that it is as simple as getting familiar with the campus of the proposed college or institute and therefore decreasing the level of stress an individual with AS may have as they begin the transition period. This is critical to ensure this period of time is perceived as positive. The same respondent also emphasised that it is essential for the student to minimise any sense of uncertainty they may have by becoming familiar with the college environment such as transport routes to the campus.

R1: *"Getting to know the bus times...talking about the morning routine…once they are prepared to go in there…to meet maybe a course director…the head of*

department…the more information somebody has the more control they feel and the less uncertainty there is".

Another key worker also highlighted the importance of these practical skills in their discussion of what strategies they assist their clients with the transition.

R2: *"Getting to know where you get lunch, where you get coffee, getting to know the entire environment from just an environmental perspective".*

Again this interviewee mentioned the importance of familiarising the client with the academic staff and building a rapport with them.

R2: *"It's about linking them with not only myself but also other people on the ground, take for example in UCC, having someone in the DSS (Disability Support Service) they've already built a rapport with, they feel comfortable speaking to if something was to come up…knowing if I become completely overwhelmed, where can I go, who can I go to".*

5.4.2 Emotional Support

The transition period can be a difficult period of time where an individual with AS may turn towards less formal providers of support such as their family and friends as a source of guidance and trust. This was mentioned particularly in one interview.

R2: *"A lot of it is about emotional support…it can be extraordinarily overwhelming when you move to college…family and friend support…so that they might be aware of how it might impact this person…supporting the friendships that already exist is a huge part of it".*

The respondents noted that it is invaluable for individuals to feel adequately supported and safe within their new environment.

R3: "*Providing a safe space, so that if they are anxious or if they are experiencing stress so that they can come talk to us, we can assure them that it is not just them that is feeling it…and give them strategies that they can use themselves, like self-directed mindfulness".*

5.4.3 Functional Support

The term functional support was mentioned specifically by one respondent but also referred to indirectly by many others in their responses as to what key strategies they employ in assisting their clients with AS.

R2: *"So we're talking timetabling, time management, study skills, using the IT labs, linking with the DSS if there is assistive technology needed…these strategies are probably what is massively key".*

5.4.4 Anxiety Management

Mental well-being was also mentioned directly in the key worker's responses. One respondent, in particular, stressed the importance of maintaining a healthy work-life balance. As the transition period has the ability to become a consuming time for the individual, the key worker mentioned the importance of ensuring that it does not become overwhelming to the extent that the student does not lose sight of other aspects of their lives.

R1: *"Anxiety management and mental wellbeing are hugely important as well because it is impossible to function really in a course unless you're feeling okay…we do a lot of work with our clients on anxiety management and having a healthy work-life balance".*

Another respondent mentioned particular types of therapies which they find beneficial for their clients.

R5: "*Using a kind of CBT or DBT type approach where you are looking at breaking down what is the antecedent, what is the emotional response, what is the physical response".*

Therapies such as Cognitive Behavioural Therapy and Dialectical Behavioural Therapy may be used to assist the clients in Aspect with their day-to-day living as they transition and become acquainted with their unfamiliar surroundings.

5.4.5 Overall Wellbeing

The key workers in Aspect are from a variety of different professional backgrounds ensuring that they bring a diverse set of skills to their clients. One interviewee mentioned the work of the Occupational Therapists as they assist their clients by working with them one-to-one on their sleeping patterns and sleep hygiene. They stressed the importance of ensuring the student winds down before they go to sleep such as the avoidance of stimulants late in the evening.

R1: "*Creating a nighttime routine, unwinding for the last few hours before bed, not looking at bright screens for the last few hours…drinking herbal teas and avoiding stimulants".*

The effectiveness of exercise in maintaining mental wellbeing was also stressed as it contributed to getting a better night's sleep and overall functioning in life and in work.

R1: *"People who struggle with their sleeping patterns, they may be quite inactive during the day and it raises their anxiety levels at night…the body isn't at rest…important to get enough exercise".*

5.4.6 Effectiveness of the Strategies

Although it is beneficial for all the various strategies discussed previously to be in operation, it is essential that they are working effectively for the clients of Aspect. Each interviewee discussed their own personal process of how they know their strategies are working effectively. Each key worker once again stressed the fact that the work they do is very much individualised. This is a positive experience for the client as they are in direct control of the process in Aspect and feel that they are once again in charge and have power over the transition period as opposed to their diagnosis being at the forefront.

R5: *"What works for one person won't work for the other".*

R4*: "Client is in control of adapting the strategy".*

As the organisation is client-centred and holds a non-dependency model, it is essential for the key workers to constantly monitor and seek feedback from their clients as to which interventions they feel are the most beneficial for them.

R5: *"On-going monitoring, evaluating, taking feedback from the clients"*.

R2: "Reporting of the clients…you see confidence growing…we as a key worker can step-back a little bit".

Increased retention rates were also mentioned as a positive sign that the strategies being used by their clients are assisting them with their mental wellbeing and that the transition period is one which they feel they can comfortably handle and overcome.

R1: "*Statistics are showing that retention rates in Universities for people with ASD who are receiving interventions are much higher"*.

5.4.7 Discusssion

The discussion on the various strategies used was one which gathered a huge amount of data from the interviewees in relation to the work carried out in Aspect to assist their clients as they transition to further education. There was a clear gap in the literature relating to this theme. Although it had been identified throughout the literature which aspects of a person with AS's life is most effected during this period, it had not explored the topic fully. The key workers within the organisation, divided their work and strategies implemented into various subheadings such as organisational skills, emotional support and anxiety management. For example, mental health had been explored in relation to anxiety being universally comorbid with AS (Tantam, 2000). The literature had mentioned a recommendation by Kapp, Gantman and Laugeson (2011) on the need for more supports and services to be provided in order to promote mental wellbeing for individuals with AS. The data collected from the participants, filled this gap in the information as it provided the researcher with knowledge of various different strategies which are used on clients with AS and which are a success.

5.5 Existing Support Services

Many of the respondents expressed their content with the existing support services available to students as they transition. One participant, in particular, discussed that there was adequate communication between various support services such as the Disability Support Service (DSS) and Aspect in UCC.

R4: *"I think there is a lot of support there at the moment…a lot of inter-disciplinary and inter-agency support and communication as well…there is a lot there at the moment that can help".*

However, other participants disagreed with this view as they discussed how a lack of communication can then lead to a lack of co-ordination between services and therefore students are left not knowing what services they could be able to benefit from.

R1*: "Communication sometimes between the Disability Support Services and lecturers can be difficult to find out information because clients may not have great communication skills".*

Another participant commented on the lack of equality throughout the different sectors of third level or further education. Many bigger colleges have far better-resourced services due to funding. However, many smaller institutes and colleges of further education are under-resourced.

R5: "*Depends on the institution, if you go to UCC, very well resourced DSS…whereas if you are in Cork College of Commerce or St. Johns, it is practically non-existent…you've got a lecturer who is double jobbing as DSS supports so that it is like woefully under-resourced".*

5.5.1 Enhancing Existing Supports

All participant were in agreement that although there were good support services in existence, there was still many which needed improvement which would benefit students. One interviewee mentioned that if there was a creation of an electronic system whereby the Disability Support Service could link in with lecturers.

R1: *"If there was some sort of electronic system that the DSS had all the information of attendance and details…relaying all that information…it can be hard to track down lecturers".*

Another participant also identified the differences between various colleges. They discussed that a local Institute has a very good academic learning centre which would be beneficial if it were also to be in all other institutes and universities. They mentioned the inclusion of non-subject specific tutors which would benefit the students more generally

as they could apply the skills they use to all entire college course as opposed to one specific module.

R4: "*There is more focus on engaging with the tutor who is less subject-specific, it is more to do with getting the skills to write an essay, how to present it well, how to submit it, researching, structuring an assignment…can be generalised across all the disciplines".*

5.5.2 Awareness

In relation to existing supports one theme which kept appearing throughout many interviews was the fact there are great services which currently exist but unfortunately, many students are not aware that they are available or may simply be afraid and apprehensive to ask for assistance.

R4: "*Hardest thing for the client is to ask for help".*

One interviewee spoke of awareness in relation to a lack of awareness about a diagnosis of Asperger Syndrome and that increased staff training in third-level and further education would benefit their clients with AS.

R2: *"Staff training…consistency".*

R3: *"A lot of it is to do with awareness…negative perceptions of AS and people might have reduced expectations for them but it is all about providing them with the right environment".*

Another interviewee stressed the fact that advertising and promotion should be examined as this would increase the chances of students who may be struggling to then have a point of contact and know where exactly they can go if they need assistance.

R1: *"The more students are made aware of the supports that are available the better…people aren't aware that counselling is available, chaplaincy, study support available, tutors".*

5.5.3 Discussion

Many interviewees mentioned the disparities between the different sectors of education in Ireland which directly reflected that which was explored in the literature. Nì Aodha (2016) discussed in the literature that difficulties experienced with Government funding,

contributed to inequalities experienced between larger universities and smaller colleges of further education where resources are scarce. Key workers in Aspect also discussed that although resources may be plentiful, that does not necessarily mean that they are being used. This was highlighted by Anckarsäter et al., (2006) and Soderstrom et al., (2002) where they explored the difficulty an individual may have accessing services due to them being inhibited by the fact they do not have the required skills to access services and resources. In 2017, the NDA released a report it which it was discussed how in Ireland there is no simple guide which outlines what services are available for individuals with autism and where a guide does exist, there has been no assessment of how well it works (NDA, 2017). This report recommended that research be carried out on what strategies and interventions are best suited for this group of individuals. The proposed Autism Bill 2017 also has this as one of its core aims.

5.6 Conclusion:

This chapter explored the finding of the five in-depth, face-to-face interviews conducted with key workers in Aspect. The participants gave an open and honest account of their work with clients who have Asperger Syndrome. They highlighted some key themes which had previously been mentioned throughout the literature. New information was also sourced which enabled the researcher to identify a substantial gap in the information and offer positive recommendations for the future.

Chapter Six: Conclusions and Recommendations

6.1 Concluding Comments:

In this research project the researcher set to explore the strategies and interventions which assist individuals with a diagnosis of AS in their transition to third-level/ further education and promote mental wellbeing. From an exploration of the literature, an understanding of the diagnosis was gotten. However, after inspection of the literature and relevant policies, it became apparent that there was a clear gap which indicated that research needed to be conducted on this crucial transition period. The transition period was highlighted as one which has the ability to cause strain in the social world of a person with AS by Kapp, Gantman and Laugeson (2011). From further exploration of policies and legislations, it became apparent that this cohort of individuals were somewhat forgotten about until the proposed Autism Spectrum Disorder Bill is implemented. Through the collection of primary, qualitative data, the five interviewees gave very informative answers which reiterated the information examined throughout the literature such as the transition period from second-level to further education and why it can be a time of added stress for individuals on the spectrum. The literature discussed the process of change of routine and environment which can have a massive impact and possibly detrimental if not managed properly. The responses from the interviews mirrored that of discussed in the literature but also added to it as they discussed in depth some of the difference between second and third-level education and how the transition is a monumental one.

While the literature discussed social deficits and particular difficulties in terms of the social arena the key workers in Aspect expanded on this. It was from this that the discussion became focused on the particular strategies and interventions which are used to assist their clients who may feel they are struggling. The work in the organisation is very much individualised much like the diagnosis of AS. The key workers spoke of how they are able to tell if the organisation's work is a success due to fact that retention rates are higher among students in third-level/ further education and also through client feedback and constant monitoring, clients are able to control the entire process, once again putting the control back in their hands.

The literature and policy reviews provided the researcher with little information regarding the supports which currently existed for students who had transitioned from second-level education. The result of unequal access to funding was discussed and highlighted that smaller colleges of further education are at a significant disadvantage when it comes to disability support and this then affects thousands of Irish students and many of Aspect's clients. The interviews provided the researcher with knowledge and recommendations on how the Government could enhance existing supports. The theme of awareness was mentioned throughout as a means of advertising and promoting the services currently available to students so as to make it easier for them to access and benefit from them. This further emphasised the point of enhancing existing supports as they are currently in place but it is a matter of making them beneficial and worthwhile for the client.

6.2 Recommendations:

It is evident from a review of literature and policy context surrounding Asperger Syndrome, that there is a clear lack of information and awareness of the diagnosis, services to assist and strategies and interventions used to aid individuals. With the forthcoming Autism Bill, it would be recommended that the transition period is given more of a regard in relation to the importance of this period in the continuation of education for individuals with Asperger Syndrome.

As mentioned in the NDA's 2017 document 'Models of good practice in effectively supporting the needs of adults with autism, without a concurrent intellectual disability, living in the community 2017', it was suggested an evaluation be conducted on what strategies and interventions are the most effective. This would assist many services who have the aim of working with clients during the transition period. The transition period emerged as a critical point and in the future, services such as Aspect and the role of the key worker are only going to become more important and perhaps should be explored as to the benefits it is creating for people with AS.

Finally, it became evident from the interviews conducted that there needs to be increased coordination between child and adult services. Currently, both are separate. Mental health services are also separate. Increased co-ordination would be for the benefit of thousands of students with AS as the transition would be able to take place earlier, decreasing the substantial amount of stress often associated with it and increasing the rates

of success for students in education and in society in general. This could also perhaps we addressed in the proposed Autism Bill.

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Appendix One: Introductory Letter



To whom it may concern,

My name is Lynn Brosnan and I am a final year student in Social Science in University College Cork. I am conducting a research project as part of my final year degree with the guidance of Nicola Maxwell, my supervisor and also in partnership with Aspect. My research project is a small scale study investigating and evaluating the key strategies and interventions used by key workers in Aspect with their clients, who have Asperger Syndrome in order to aid them as they transition to further education and aid their mental wellbeing.

I would be grateful if you would take part in a short interview in relation to my research topic which will consist of open-ended questions. I will be available to conduct my interviews when it suits you best. Here I attach an information sheet and consent form. Please do not hesitate to contact me if you have any questions at 115329616@umail.ucc.ie.

Thank you for your participation.

Yours sincerely,

Lynn Brosnan.

Appendix Two: Information Sheet



Purpose of the Study. As part of the requirements for the Bachelor of Social Science Degree at UCC, I have to carry out a research study. The study is concerned with investigating and evaluating the key strategies and interventions used in promoting mental wellbeing in young adults with ASD as they transition from adolescence into further education.

What will the study involve? The study will involve a series of 15 minute interviews where I will ask questions regarding the key interventions used by workers in Aspect which assist their clients in the transition to further education.

Why have you been asked to take part? You have been asked because as a key worker in Aspect you can provide the relevant knowledge in regards to the strategies and interventions used with clients.

Do you have to take part? No, you do not have to take part. Prior to taking part, participants will sign a consent form but are free to withdraw at any time before the study has commenced even if the consent form has been signed, or after data collection has commenced. There will be a two week period after the data has been collected in which you are free to contact the researcher to have the data they provided destroyed.

Will your participation in the study be kept confidential? Yes. I will unsure all data collected will remain anonymous to the utmost of my ability as the organization Aspect will be named and referred to, however all personal information in regards to participants will remain confidential and any direct quotes or extracts used will remain entirely anonymous.

What will happen to the information which you give? The data will be kept confidential for the duration of the study, available only to me and my research supervisor. On completion of the project, data will be retained for minimum of a further ten years and then destroyed. Any physical data pertaining to the project will be kept in a secure place and consent forms and all other identifying information will be kept separate. This data

can be destroyed after analysis. All electronic versions will be stored for the minimum of ten years as per the university policy and will be stored in a laptop which is password protected.

What will happen to the results? The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. The study will be published on the Community Academic Research Link (CARL) website as part of the initiative it is part of and studied in relation to recommendations which may arise from it.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience in this way may cause some distress.

What if there is a problem? At the end of the procedure, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, you should contact the investigator, Aspect, or your GP.

Who has reviewed this study? Approval must be given by the Social Research Ethics Committee of UCC before studies like this can take place.

Any further queries? If you need any further information, you can contact me:

Lynn Brosnan

115329616@umail.ucc.ie

Nicola Maxwell

n.maxwell@ucc.ie

Appendix Three: Consent Form

I……agree to participate in Lynn Brosnan's research study.

The purpose and nature of the study has been explained to me in writing.

(1) I am participating voluntarily.

(2) I give permission for my interview with Lynn to be audio-recorded.

(3) I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

(4) I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

(5) I understand that anonymity will be ensured in the write-up by disguising my identity.

(6) I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:
(Please tick one box :)

I agree to quotation/publication of extracts from my interview □

I do not agree to quotation/publication of extracts from my interview □

Signed: …… Date: ……..

PRINT NAME: ……

Appendix Four: Ethics Form

Complete this check list and discuss *with* your supervisor

If your answer falls into any of the shaded boxes, please address each point later on in the form.

		YES	NO	N/A
1	Have you discussed your proposed research and your ethical review with your supervisor?	X		
2	Do you consider that this project has significant ethical implications?		X	
3	Will the main research procedures be outlined to potential research participants in advance, so that they are informed about what to expect?	X		
4	Will research participation be voluntary?	X		
5	Will informed consent be obtained in writing from research participants?	X		
6	Will you tell research participants that they may withdraw from the research at any time and for any reason, and (where relevant) omit questionnaire items/ questions to which they do not wish to respond?	X		
7	Will data be treated with full confidentiality/ anonymity (as appropriate)?	X		
8	Will data be securely held for a minimum period of ten years after the completion of a research project, in line with the University's *Code of Research Conduct* (2016)?	X		
9	If results are published, will anonymity be maintained and participants not identified?	X		
10	Will participants be debriefed at the end of their participation (i.e. will you give them a brief explanation of the study and address any concerns they may have after research participation)?	X		
11	Will your project involve deliberately misleading participants in any way?		X	
12	Will research participants include children/ young persons (under 18 years of age)?		X	
13	If yes to question 12, is your research informed by the UCC *Child Protection Policy*? http://www.ucc.ie/en/ocla/policy/		X	
14	Will your project require you to carry out "relevant work" as defined in the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016?		X	
15	Do you require official Garda Vetting through UCC before collecting data from children or vulnerable adults?		X	
16	Will research participants include people with learning or communication difficulties?		X	
17	Will research participants include patients/ service users/ clients?		X	
18	Will research participants include people in custody?		X	
19	Will research participants include people engaged in illegal activities (e.g. drug taking, illegal Internet behaviour, crime, etc.)?		X	
20a	Is there a realistic risk of participants experiencing either physical or psychological distress due to research participation?		X	
20b	Is there a realistic risk of you, as the researcher, experiencing either physical or psychological distress?		X	
21	If yes to question 20a, has a proposed procedure for linking the participants to an appropriate support, including the name of a contact person, been given?			X
22	If yes to question 20b, has a proposed procedure/support structure been identified?			

23	Are the research participants also students with whom you have some current/previous connection (class members, friends, tutor, etc.)?		X	
24	Will research participants receive payment/ gifts/ vouchers/ etc. for participating in this study?		X	
25	Are you accessing, collecting or analysing confidential agency documents or case files? If yes, please give details of compliance with the agency's policy on data protection and confidentiality below in your review.		X	

If you did not tick any shaded boxes proceed to Part A and complete the relevant form. If you did tick shaded boxes please proceed directly to Part B and complete the relevant form.

PART A: DESCRIPTION OF THE PROJECT

*Ethical review requires that you **reflect** and seek to **anticipate** ethical issues that may arise, rather than reproduce copious text from existing research proposals into these boxes. Entries should be **concise** and relevant to the point/ question.*

A. Very brief description of your study (15-25 words max.)
[e.g. This is a narrative literature review (desk-based) examining group work interventions with young people on the theme of sexual health]

This is a small qualitative study of key workers in Aspects and the key strategies and interventions they use on clients to promote mental wellbeing.

B. What is your study about? (Aim and Objectives / Key Research Questions) (100-150 words max.)

This study is examining how the transition period for a young person with high functioning autism and without an intellectual disability into third-level education can be a period of time where their mental wellbeing may be affected. It is a period of time where extra supports are needed and key workers in aspect are providing their clients with various coping mechanisms and strategies to support them in terms of their mental health and their transition. The data collected through this study will provide the public with information in regards to which interventions and strategies work well and assist their clients and which can also be improved on in order for individuals with autism to feel adequately supported.

C. Concise statement of *anticipated* ethical issues raised by your project. How do you intend to deal with them? For example, your research could be desk-based but may still involve sensitive/ controversial material (100-150 words max.). In relation to any kind of research with human subjects you need to address the issue of **informed consent** and how that will be addressed, **safe data storage** for the duration of the project and beyond and how you will safeguard the **rights and welfare of research subjects.** If research is being conducted with **any** human subjects, information leaflets, consent forms etc., which have supervisor oversight, should be routinely used.

As all the participants in the study are from the same organisation, Aspect, there is a likelihood that the participants will know each other. However, I will keep all information in regards to the participants anonymous and information published in this piece of research will be done in a way as that participants will not be identified. Pseudonyms or letters will be assigned to the participants so that their real name or identity is concealed. I will be storing both physical and electronic data for a minimum on 10 years. Physical data will be stored in a secure cabinet and electronic data will be stored using a password protected device. Prior to the publishing of this study, the only people who will have access to this data will be the researcher and supervisor. This piece of research will be published on the UCC CARL website where members of the public will be able to access it yet all participants' information will remain anonymous.

Appendix Five: Interview Guide

Aspect's Work

1) Why do you feel your clients with Autism Spectrum Disorder require extra support?
2) Do you feel your client's mental wellbeing is impacted during their transition from adolescence to adulthood in relation to further/third-level education?
3) What strategies do you use with your clients to combat these struggles experienced?
4) How do you know they benefit your clients?

Strengthening supports for students with ASD

5) How do you think existing student supports in institutional settings might be enhanced for the benefit of students with ASD, in terms of mental well-being?
6) Are there other supports, in your view, which would benefit students with ASD in transitioning to further/third-level education?
7) Is there anything else you would like to add to this discussion area?