CORA Cork Open Research Archive
Cartlann Taighde Oscailte Chorcaí

Title	An exploration of the views of adults with Asperger syndrome/ high functioning autism in relation to independent living
Authors	Coogan, Gillian
Publication date	2014-05-06
Original Citation	Coogan, G. (2014) An exploration of the views of adults with Asperger syndrome/high functioning autism in relation to independent living. Cork: Community-Academic Research Links, University College Cork.
Type of publication	Report
Link to publisher's version	https://www.ucc.ie/en/scishop/rr/
Rights	©2014, Gillian Coogan.
Download date	2026-11-06 18:54:35
Item downloaded from	https://hdl.handle.net/10468/8726

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

An Exploration of the Views of Adults with Asperger Syndrome/High Functioning Autism in Relation to Independent Living.

Gillian Coogan

CARL Research Project

Name of student(s):	Gillian Coogan
Name of civil society organization/community group:	Cork Association for Autism
Supervisor(s):	Mary Mc Govern/ Lydia Sapouna
Name and year of course:	BSW(hons)2014
Date completed:	06/05/14

What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a service provided by research institutes for the Civil Society Organisations (CSOs) in their region which can be grass roots groups, single issue temporary groups, but also well structured organisations. Research for the CSOs is carried out free of financial cost as much as possible.

CARL seek to:

provide civil society with knowledge and skills through research and education;

provide their services on an affordable basis;

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

enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

What is a CSO?

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

Why is this report on the web?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public. We are committed to the public and free dissemination of research results.

How do I reference this report?

Author (year) Project Title, [online], School of Applied Social Studies, Community-Academic Research Links/University College Cork, Available from: http://www.ucc.ie/en/scishop/completed/ [Accessed on: date].

How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?

The UCC CARL website has further information on the background and operation of the Community-Academic Research Links at University College Cork, Ireland. http://carl.ucc.ie

CARL is part of an international network of Science Shops. You can read more about this vibrant community and its activities on this website: http://www.scienceshops.org

Disclaimer

Notwithstanding the contributions by the University and its staff, the University gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Client Group, or users, to ensure that any outcome from the project meets safety and other requirements. The Client Group agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed to a very high standard and to the satisfaction of the Client Group.

Acknowledgements

I wish to thank the research participants. This study would not have been possible without your honesty, bravery and openness. To Yvonne Scriven and all the wonderful staff of ASPECT and the Cork Association for Autism, I thank you for your ideas, your kindness and your patience.

I would like to thank my tutors Mary Mc Govern and Lydia Sapouna for their support and enthusiasm throughout this process.

To Kenneth Burns, Anna Kingston and the CARL Committee, I am eternally grateful to have been given this opportunity.

I am indebted to Jennifer who has encouraged and supported me throughout this four year roller coaster and to Linda who taught me to dream bigger dreams for myself. You both inspire me every day.

Finally, thank you to my wonderful family who sacrificed so much so that this project would come to fruition. To PJ who learned to cook and to my wonderful twins who would leave me in solitude so that I could study, I will never forget the sacrifices that you made. Without your support and understanding this project would never have begun, thank you.

Abstract

This research study aims to explore the views of adults with Asperger Syndrome/High Functioning Autism in relation to independent living. This study forms part of the assessment criteria for the Bachelor of Social Work (hons) degree at University College Cork. It is also a collaborative project between the Cork Association for Autism and the researcher as part of the University's Carl project.

As a social work student the researcher recognises the importance of empowering the client in making decisions for themselves and also acknowledging their right to participate fully in society. Historically the concept of independent living has been associated with living alone, however the researcher would argue that many people do not live on their own and yet would consider themselves to be living independently.

To date research on independent living has been from the perspective of the professional. In order for this study to be a congruent reflection of the clients' experiences, it was essential that the client be pivotal to the primary research. This study combines both primary and secondary research. The findings were analysed using interpretative phenomenological analysis and the researcher hopes that the findings and recommendations will inform future service provision. The researcher also hopes that in terms of the perceptions regarding the ability of people with Asperger Syndrome, that a more positive discourse will emanate as a result of the findings of this study.

Table of Contents:

Title Pages.....1
Acknowledgements.....4
Abstract.....5
Contents Page.....6
Chapter One: Introduction
1.1 introduction.....9
1.2 Title.....9
1.3 Overview of chapters.....9
1.4 Background to the Study.....10
1.5 Explanation of terms used.....10
1.6 Definition of independent living.....11
1.7 Rationale for the Research.....11
1.8 Research Aims.....12
1.9 Research Objectives.....12
1.10 Research Questions.....13
1.11 Conclusion.....14
Chapter Two: Literature review
2.1 Introduction.....15
2.2 Social isolation.....15
2.3 Executive functioning.....16
2.4 Depression/anxiety.....17
2.5 Theory of mind.....18
2.6 Legislation.....19
2.7 Conclusion.....19
Chapter Three: Methodology
3.1 Introduction.....21
3.2 Designing the research instrument.....21
3.3 Demographic table of participants.....23
3.4 Ethical considerations.....23
3.5 Research approach.....24
3.6 Qualitative research.....25

3.7 Participatory research.....25
3.8 Theoretical perspective.....26
3.9 Choosing the research participants.....27
3.10 Gender imbalance..... 27
3.11 Limitations- purposive sampling..... 28
- interpretative phenomenological analysis.....28
3.12 Conclusion.....29
Chapter Four: Findings and Analysis:
4.1 Introduction.....30
4.2 Data analysis 30
4.3 Methodology.....31
4.4 Overview of key findings:
Theme one: Definition of independent living.....32.
Theme two: Barriers to independent living.....32
Theme three: Impact of AS characteristics upon independent living
- Organisation and planning.....33
- Domesticity and independent living.....33
- Social challenges/Theory of mind.....34
- Stress/Depression/Anxiety.....35
Theme four: Hopes for the future.....36
4.5 Reflexivity- the researcher's position.....36
4.6 Conclusion.....37
Chapter Five: Recommendations:
5.1 Introduction.....38
5.2 Recommendations.....38
Independent Living Module/Assisted Daily Living.....38
Transitional Workshop for Parents.....39
Independent Living Advocate.....39
Future Recommendation- Aspect Supported Housing.....40
5.3 Implications for social work practice.....40
5.3 Author's comments.....41
5.4 Conclusions.....41
Bibliography:.....10
Appendix 1 Asperger Syndrome.....49

Appendix 2 Aspect.....50
Appendix 3 Changes to DSM V.....53
Appendix 4 Letter for Aspect.....55
Appendix 5 Letter for participants.....56
Appendix 6 Information sheet for participants.....57
Appendix 7 Questionnaires.....58
Appendix 8 Informed consent letters.....61
Appendix 9 CARL research agreement.....62

Chapter One
Introduction

" Not everything that steps out of line, and thus 'abnormal' must necessarily be inferior"
(Hans Asperger, 1938 cited in Attwood, 2007:11).

1.1 Introduction to Chapter:

This chapter will introduce the reader to the topic. The chapter format, background and rationale for the study will be outlined as well as the aims and objectives of the research.

1.2 Title:

An exploration of the views of individuals with Asperger Syndrome/High Functioning Autism in relation to independent living.

1.3 Overview of chapters:

This study is comprised of five chapters, outlined as follows;

Chapter one:

Introduces the reader to the topic, presents the rationale for the study, defines independent living and outlines the aims and objectives.

Chapter two:

Provides an overview of the methodology, including the ethical issues, and the design of the research instrument.

Chapter three:

Discusses the current discourses in the literature and provides an overview of the legislative framework which underpin independent living.

Chapter four:

Contains a table outlining the demographics of the participants and discusses the findings of the focus group and questionnaires.

Chapter five:

Presents the recommendations and conclusions of the researcher.

1.4 Background to the Study:

This study was a collaborative research project between the researcher and the Cork Association for Autism (hereafter known as CAA). The CAA, based at Greenville House Carraigtwohill was founded in 1978. They provide day, home and residential supports and respite for adults with Autism. By using a person-centred and individualistic approach they aim "*to provide a high quality, stimulating and caring environment to those with autism, in a 'home-like' non-clinical environment"* (CAA, 2014). In 2007 they established a new service ASPECT which caters specifically for adults with Asperger Syndrome (hereafter known as AS). See Appendix 2 for further information on Aspect.

The researcher has professional and personal insight into the difficulties experienced by people with disabilities in relation to the general perception of their ability to live independently. Whilst attending multi-disciplinary team meetings in the past, the researcher was intrigued that some medical professionals equated the ability to live on one's own with the ability to live independently . The researcher would argue that as *"man is by nature a social being"* (Aristotle, 1797:159) the concept of living alone except when by choice, is anomalous. And furthermore would contend that there are many people who do not live alone for economic or personal reasons and yet would consider themselves to be living independently.

Given the paucity of research into independent living from the client perspective, it was essential to the researcher that all the participants who were interviewed as part of this study were all Aspect clients. Both the researcher and the CAA hope that the findings and recommendations from this research will provide guidance as to future service provision.

1.5 Explanation for terms used:

The primary manual used by clinicians to diagnose AS is the Diagnostic and Statistical Manual (DSM) from the American Psychiatric Association (APA) and the ICD 110 from the World Health Organisation (WHO). Until recently conditions such as Autism, Childhood Dis-integrative Disorder, Asperger Syndrome and Pervasive Developmental Disorder were classified separately. However the introduction of the recent DSM 5 has meant that now all four are under the umbrella term 'Autism Spectrum Disorder'(ASD). However for the purpose of this study the researcher will use the term Asperger Syndrome/High Functioning Autism as many professionals continue to use these terms and the

participants of this study also identified with them. Further information regarding the changes in the DSM 5 are in Appendix 3.

Asperger Syndrome was first discovered in 1944 by Dr. Hans Asperger. He observed that some children displayed typical characteristics of autism but their intelligence quotient was within the average range. The term High Functioning Autism (HFA) was first used by Lorna Wing in 1981 (Mesibov et al, 2001). This term was used to describe children who displayed the stereotypical autistic characteristics but were cognitively more higher functioning those diagnosed with traditional autism. Their cognitive abilities were similar to that of children with AS (Attwood, 2007). Despite these similarities which have resulted in the two being used interchangeably, HFA is not recognised by the DSM 5 or the ICD-10. However for the purposes of this study both these terms will be used. AS is described as the *"hidden disability"*
(The National Autistic Society, 2014). And it features a triad of impairment: social communication, social interaction and social imagination. Unlike Autism, an individual with AS will not have a learning difficulty. For further information on Asperger Syndrome see Appendix 1.

1.6 Definition of independent living:

Independent living as a concept is not based solely on geography. Mc Gettrick argues that in order for a person to live independently it is not sufficient to only provide adequate housing, personal assistance and accessible transport. Independent living he states also *"requires the recognition of an individual's civil and human rights, the empowerment of disabled people to exercise choice and control over their own lives as well as their engagement in the decision-making process"* (Quin & Redmond, 2003:68). The researcher is of the opinion that historically independent living has been equated with living on one's own. However the researcher's own perspective is that independent living is a subjective term and would argue that many people live very independent lives and yet do not live on their own. The concept of independent living is discussed in greater detail in chapter two under the section on legislation.

1.7 Rationale for the Research:

To date there have been very few studies based on the experiences of adults with AS from their own perspective. Griffith et al (2011) highlighted during their research that adults on

the high functioning end of the autistic spectrum have been rarely studied. Heffernan & Neilson (2013) state that there is very little research from an Irish perspective. Historically, teaching modules on disabilities tend to focus only on the Autism element of an Autistic Spectrum Disorder. As a result the only perspective is from that of the professional. The researcher would argue that as professionals we cannot advocate for appropriate service provision in relation to independent living without understanding what the needs are. As a future social worker, the researcher has extensive personal insight and knowledge into the challenges associated with Autism but has limited understanding of Asperger Syndrome. It is therefore imperative for continuous professional development that we engage with people with AS and ascertain their views on the supports and services which they believe they need to live as independently as possible.

This study also forms part of the assessment criteria for the Bachelor of Social Work (hons) degree based at University College Cork (UCC) and is a requirement for participants in the UCC Science Shop CARL projects. The UCC Science Shop facilitates research partnerships between community organisations and UCC students (CARL, 2013). By using a collaborative approach, all parties involved shared in the responsibility and control for this project.

1.8 Research Aims:

The aim of this research is to gain insight into how an adult with AS defines independent living, the difficulties they have encountered whilst pursuing this independent lifestyle and the factors which enhanced this process. To date research around this topic has identified lack of organisation, inability to manage finances and social isolation as the key barriers in relation to independent living (Redmond & Bear don, 2008),(Muller et al, 2008), and (Griffith et al, 2012). However the researcher wanted to ascertain if there were other prevalent issues which could be addressed practically by service providers.

1.9 Research Objectives:

In order to explore the views of adults with AS in relation to independent living, the researcher facilitated a focus group of six Aspect clients and also conducted a literature review to gain insight into current discourse and re-occurring themes around this topic. Prior to attending the focus group the participants were also given a questionnaire to complete, the rationale for this will be discussed in chapter four. By interviewing adults

with AS as opposed to professionals working in the area, the researcher hoped to gain insight into how adults with AS define independent living and also their experiences of same. The researcher also envisaged that this study once completed and the findings presented to the CAA, would form the basis for future dialogue and possible further studies within the CAA and other organisations. In terms of public and professional perceptions regarding the ability of a person with AS to live independently, the researcher hopes that a more positive discourse will emanate as a result of the findings of this study.

1.10 Research Questions:

In conducting this participatory piece of research it was essential that the language used in the questionnaires was respectful to the participants. The researcher and the CAA agreed that any terms which implied disablement would not be used. The word '*diagnosis'* would also not be used and the researcher agreed that the participants would not be asked any questions specifically relating to their AS, as this was not the focus of the interviews. However it was agreed that the characteristics of AS would be referred to in the questionnaires so that the researcher could understand how these might impact upon independent living.

Key questions included;

- How do adults with AS define independent living?
- What do they perceive as the greatest barrier to independent living?
- If it were possible would they choose to live on their own?

The researcher believes that the answer to the last question is particularly relevant as historically the perception is that in order for a person to live an independent life, they must live alone. Research by Rent & Eyers in 2006 highlighted that of 58 participants, 10.3% lived independently, 8.6% with a partner, 55.2% with parents and 25.9% in supported/residential living. The researcher was intrigued to note that the 8.6% who lived with a partner were not classified as living independently. And this researcher would argue that in today's society many adults live with their parents, siblings or in shared accommodation for economic reasons and yet would consider themselves to be living an independent life. As a result this researcher would contend that linking the concept of independent living with living alone could be fallacious.

1.11 Conclusion:

In this chapter the researcher introduced the reader to the topic, provided an explanation for key terms used, outlined the aims and objectives and rational of the study. Some of the definitions used in this chapter will be discussed further in the next chapter on the literature review.

Chapter Two
Literature Review

"Characteristics of ASD mean that you bring a unique perspective to life and have much to offer", (Tickle & Scott, 2010:46).

2.1 Introduction:

Due to the participatory nature of this study, the researcher and the CAA collaborated as to which literature should be reviewed. Key seminal works by adults with AS were studied along with existing journal articles, blog-sites and other publications. As the focus of this study was the concept of independent living, all research regarding the transition to second and third level education was excluded. Quin & Redmond (2003) state that the concept of independent living for people with disabilities was born from the disability activism of the 1970s. The researcher therefore excluded all research prior to this date.

During the initial literature search, the researcher noted that there was a paucity of studies into independent living and there was also a distinct lack of research from the client perspective. A key theme which emerged from the literature reviewed is that the majority of individuals with AS are still highly dependent on their families for support. Larsen and Mouridsen's study of nine individuals with AS in 1997, found that five of the participants had their own home and lived independently, or with minimal supports. Whilst a London based study of 19 young men found that only three lived independently (Howlin et al., 2000: Mawhood et al., 2000). And a study by Good et al (1999) revealed that only three of the 75 individuals lived independently. To explore possible reasons for this high level of dependency, the researcher grouped these findings thematically as follows; social isolation, executive functioning, depression/ anxiety and theory of mind.

2.2 Social isolation:

An extensive body of literature exists which identifies that a contributing factor leading to participants' social isolation is their difficulties with social and communication skills. Macloed found that in the case of people with AS, *"their difficulties with social and communication skills cause them to become alienated from their peers, and make it very hard for them to lead an appropriate social life"* (Macloed, 1993:180). She also highlighted

that, "*social integration within a peer group is an essential step to being accepted by society and is thus an important factor in self-esteem"* (ibid). She also states that the importance of a social life cannot be overestimated. She cites research by Wing (1990:186) who says that social impairment *"has a particularly devastating effect because it cuts off those affected from the ordinary sources of learning and emotional support other beings can provide"*. And a study of 18 adults with AS found that all but one of the participants had reported intense social isolation (Muller et al 2008).

The social difficulties associated with AS can also have a negative impact upon quality of life. Coussens, in comparing the quality of life for men with and without AS found that 11 of the 12 participants without AS engaged in activities mainly with friends compared with just six men with AS. In summing up she stated that *"Asperger Syndrome has an impact on quality of life"* (Coussens et al 2006:412).

Research by Griffith et al .(2011:538) highlighted that the majority of the participants stated that they had extreme difficulty in initiating social interactions. *"Social Interaction was perceived by participants as being fraught with potential problems".* Many participants expressed difficulties with informal socialisation in the work place and believed despite their intelligence and ability to perform to a high standard, that this impacted upon their career potential. And more recent findings from research by Van Heijst & Geurts (2014) revealed that the most affected domain regarding quality of life was social functioning.

2.3 Executive functioning:

Executive functioning is a mental skill which has two facets: organisation and regulation. An inability to regulate one's behaviour and speech can impact upon independent living and in terms of organisation, many individuals with AS have deficits in cognitive functioning (Neilson & Heffernan, 2013). These deficits can create difficulties in the ability *"to organise, sequence and prioritise"* (The National Autistic Society, 2014). This inability can often be a source of anxiety and stress. One of the key themes which emerged from the literature was the impact that this inability to perform basic tasks had upon independent living. Beardon and Edmonds (2008) stated that individuals with AS can struggle with organisation, time-management and prioritising. And a study of 12 participants with AS by Coussens et al. (2006:409) highlighted that some participants "*were not able to live independently as they could not handle all the tasks needed such as*

cooking, doing laundry or managing finances".

Neilson and Heffernan, (2013:89) highlighted that there are four neurological factors related to AS which obstruct the individual's ability to organise and complete tasks. These are,

- *"Poor executive functioning. This can impact upon short-term working memory, attention span, problem solving, verbal reasoning and impulse control.*
- *Sensory processing difficulties. This can create hyper and hypo sensitivity as well as sensory integration dysfunction and synaesthesia.*
- *Preservation or obsessiveness. Rigidity and an inability to move onto the next task or topic.*
- *Lack of social imagination. A difficulty in coping with situations where the outcome is unknown".*

All of these can impact upon the ability to concentrate in the workplace which may prevent the individual with AS from obtaining employment. And an inability to work can create a financial barrier to living independently.

2.4 Depression and anxiety:

"Depression is a common trait in people with AS. How could they not be depressed when the world doesn't understand them, doesn't connect emotionally to them and doesn't understand the things which drive them" (Bollard, 2007). Research by O Mazurek (2013:223) highlighted that *"rates of depressive symptoms increase with age amongst individuals with ASDs. And adults with ASDs are at significantly greater risk of mood and anxiety disorders than are individuals in the general population".* A primary finding was that "*loneliness was significantly correlated with increased depression and anxiety, and decreased life satisfaction and self-esteem"* (ibid). Neilson & Heffernan (2014:34) compare *"the effects of social impairment, emotional processing and sensory reactions"* to the feeling that one is always on the edge and rarely relaxes or feels safe. And these feelings, they state *"can have a lifelong effect on psychological well-being"* and the most *"immediate effect is anxiety".*

Temple Grandin a professor at Colorado State University, world renowned author, animal activist and an engineer was diagnosed with an ASD at age two. She described her

feelings of anxiety as if she were in a constant state of hyper vigilance
(Tinsley & Hendrickx, 2008). The impact of depression and anxiety is one that the researcher was keen to explore with the participants, and equally the stress-ors which trigger these feelings.

2.5 Theory of mind:

Theory of mind "*refers to one's ability to perceive how others think and feel. It can be summed up as a person's inability to understand and identify the thoughts, feelings and intentions of others" (Autism Speaks, 2014).* This lack of theory of mind can create a situation where a person with AS may not recognise whether the intentions of another are genuine or not, a condition known as *mind-blindness.* This can create situations where a person with AS may be subjected to manipulation or bullying or difficulties in considering the perspectives of others. Smith & Southwick (2013:8-9) noted that people who have deficits in the area of theory of mind have *"difficulty understanding the emotions and mental states of others".* They subdivide theses deficits into the following categories;

1. *Difficulty explaining own behaviours: even though a person with AS is highly verbal, they have difficulties explaining why they did something.*
2. *Difficulty understanding emotions: not only do persons with AS have difficulty recognising the emotions of others, they often have problems understanding their own feelings.*
3. *Difficulty predicting the behaviour or emotional state of others.*
4. *Problems understanding the perspective of others.*
5. *Problems inferring the Intentions of others.*
6. *Lack of understanding that behaviour impacts how others think and/or feel: many people with AS do not make the connection between their actions and others' reactions to them.*
7. *Problems with joint attention and other social conventions: persons with AS have difficulties with turn-taking, perspective-taking, politeness, and numerous other social conventions.*
8. *Problems differentiating fact from fiction* (ibid).

2.6 Legislation:

The UN Convention on the Rights of Persons with Disabilities is the first legally binding instrument which protects the rights of person with disabilities. Article 19 states that,

"Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement" (National Disability Authority, 1996). The European Union Charter of Fundamental Rights, Article 26-'Integration of Persons with Disabilities' states that, *"the union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community"* (Council of Europe, 2008). And 'The International Covenant on Economic, Social and Cultural Rights(ICESRC) was ratified by Ireland in 1989. Under Article 11 a person with disabilities has the right to "*the continuous improvement of living conditions".*

The Health Service Executive Report *National Review of Autism Services Past, Present and Way Forward* (2012) recognised that *"a range of services/supports are necessary to meet the diverse needs of adults on the autistic spectrum to enable them to be as independent as possible and to lead fulfilling lives within their own communities".* However to date there is no legislation from an Irish perspective which governs the provision of ASD specific service provision.

In 2012, Labour TD Michael Mc Carthy introduced a private member's bill known as the Autism Bill. This Bill would place a statutory obligation on the State to provide services for adults with ASD. This bill would ensure a more equal delivery of services across the country in terms of health, housing, economics and social service. This will be the first ASD specific piece of legislation and it is hoped that it will replicate the Autism Act (2009)England and the Autism Act (2011)Northern Ireland which places definitive obligations on Local Authorities and the NHS in terms of appropriate service provision. To date however there has been no progression with this Bill (Irish Society for Autism, 2014).

2.7 Conclusion:

Having reviewed the literature the researcher grouped it under four themes for the purposes of analysis and also to provide insight into possible topics for discussion during the focus group. Social isolation, difficulty with executive functioning and theory of mind

and depression/anxiety were the key themes throughout. The lack of legislation in terms of appropriate State provision of housing for individuals with AS was highlighted by many of the researchers. Although the proposed private member's Autism Bill seeks to address this disparity, the researcher would be concerned that in the current economic context the Bill and its proposed service amendment may never come to fruition.

Chapter Three
Methodology

"We're often risk adverse or as the books say, 'change resistant', but it doesn't mean that we can't accept change. Give us enough acceptance and support, make sure that too much doesn't change at once and make sure that we have something solid to cling to and we'll make the change..... Eventually". (Gavin Bollard, 2013).

3.1 Introduction:

To ensure that this research study was from the client perspective, a qualitative and participatory approach was used underpinned by an interpretative phenomenology. In this chapter the researcher will outline why both primary and secondary research was used in the research design of this participatory study. She will explain the criteria for choosing the participants and the ethical considerations in using this group. The benefits of using focus groups and questionnaires will be discussed. In the final section of this chapter, the researcher will discuss the limitations of this study and also examine the social construction of disability. This is an area of interest to the researcher given the changes to the DSM 5. Prior to 2013 a person would have been clinically diagnosed with Asperger Syndrome however now the same person will be diagnosed with an ASD and the term Asperger Syndrome will no longer be applied to that individual.

3.2 Designing the research instrument:

The researcher decided to use both primary and secondary research. The rationale for this is outlined in the section below entitled qualitative research. The researcher and the CAA agreed that the study would consist of a focus group as opposed to individual interviews. As all the participants were Aspect clients, in using a focus group they were able to communicate with and support each other during the process (May, 2011). The CAA also requested that a general list of questions be compiled and given to the participants prior to the focus group. The rationale for this was that some of the participants wanted to see the questions beforehand, whilst others wanted the option to submit their answers at a later stage. The researcher and the CAA were also concerned

that without prior knowledge of the questions, some of the participants would become anxious. Attwood (1998) states that anxiety in a person with AS stems from uncertainty and changes in routine. In order to ensure that the participants were comfortable with the process, the questionnaire was compiled by the researcher and approved by the CAA. This questionnaire was brief and contained mainly classification questions for demographic purposes. There were also a number of questions relating to participants' own personal experiences. This also ensured that ethically the participants were aware of exactly what information was required from them and that they understood what was expected of them (May, 2011).

Of the six participants in the study, two returned the questionnaire prior to the focus group, two presented them on the night and the remaining two said that they would prefer to just speak during the focus group. The focus group followed a semi-structured format as there was a pre-existing agenda for the research. This allowed the researcher to further explore the participants' experiences and gave greater flexibility in terms of the direction of the group whilst still providing structure and clarity for the participants. By utilising this format the group were able to interact more naturally with each other and the researcher was able to monitor non-verbal expressions and pauses. There were several incidences when the researcher observed participants empathising with and offering suggestions to each other. Historically research on people with AS has highlighted an inability to empathise with the situations of another, however the researcher was inspired by the way that this group supported each other. This will also be discussed in chapter four; findings and analysis.

As the researcher's goal was to encourage the participants' engagement she was aware that some individuals may have been reluctant to participate during the focus group. The CAA and the researcher's own tutor provided guidance and advice in relation to this. The researcher's contact person within Aspect suggested that the participants should be given a questionnaire prior to the focus group to facilitate those would may not contribute on the night but who would still want to participate. The focus group was recorded on a Dictaphone and was transcribed verbatim. The collected data was coded thematically and analysed using Interpretative Phenomenological Analysis (IPA).

3.3 Table 1. Demographic information of participants.

Participant	Age	Gender	Status	Occupation	Current Living Status
1	27	F	Single	Started Work experience	With mother
2	27	F	Single	Trainee chef	On her own
3	23	F	Single	Full-time student	With parents
4	27	M	Single	Full-time student	House share with 2 students
5	23	M	Single	Full-time student	With parents
6	27	M	Single	Unemployed / Unpaid Work-Experience	With parents at the weekend and a flat share during the week

3.4 Ethical Considerations:

The UCC Code of Research Ethics section 8.2 states that the *"researcher should give particular attention to safeguarding the rights and dignity of vulnerable individuals and groups who participate in research".* When the researcher initially met with the CAA, the issues of ethics was discussed. Generally research relating to the experiences of people with disabilities tended to be from the perspective of the professionals, carers and/or family members as opposed to the client. As one of the aims of this research was to gain an understanding of the experiences of people with AS and independent living, the researcher was aware of the possible lack of objectivity by not using clients. As a result, the researcher and the CAA agreed that both primary and secondary research would be conducted. As a result six Aspect clients were chosen by the CAA as suitable candidates for the focus group. All of the six were deemed to have full capacity to consent to participate in this research. The researcher's tutor agreed that there were no ethical issues with this group. The researcher also gave a letter to the Director of Services of the CAA outlining the procedure for collecting and storing of the data and destruction of same six months after the project is completed. Regarding the participants themselves, due to the

variance of characteristics in adults with AS, the location for the interview and length of the interview was at their discretion. May (2007:141) states that *"clarification is not only a practical but also an ethical consideration"* therefore the researcher and the CAA ensured that all participants were informed of the nature and purpose of the study. The researcher also supplied them with an information pack (See Appendices 5-8). Contents included:

- An out-line of the research study.
- The aims and objectives.
- A copy of the consent form and a stamped address envelope.
- A copy of the questionnaire. The wording of which was discussed with the CAA prior to compiling to ensure that the language was appropriate and explicit.

Participants were informed that the focus group would be recorded and that they could withdraw at any stage from the process. They were also informed that the report would be published and would appear on the UCC website. Although the participants were not promised confidentiality there were informed that all information pertaining to them would be anonymised. As the researcher was aware that *"what the participants tell the researcher is inherently shared with the group participants as well"* (Morgan, 1996:32), she informed the group that they also had an obligation to respect the confidentiality of the other participants. Due to the possible sensitive nature of a focus group with these participants an agency contact person was available throughout the process should anyone have needed additional support.

3.5 Research Approach:

In order to participate in this research study all of the participants needed to have a diagnosis of AS. To obtain a representative sample, a purposive sampling technique was used. Purposive sampling technique is a category of non-probability sampling. The participants are not chosen at random but instead are chosen based on a shared knowledge or experience (May, 2011). As the researcher planned to use interpretative phenomenological approach in the analysis, at least five participants were needed. Ten possible clients were identified however only six agreed to participate. Both the researcher and the CAA were aware of the sensitive nature of this topic and the issues which may arise from engaging clients with AS in primary research. However Lorna Wing (cited in Attwood, 1998:9) states that *"people with Asperger Syndrome perceive the world differently from everyone else"* and because it was important to both the researcher and

the CAA that the findings of this study would be an authentic reflection of the views of individuals with AS, it was agreed that both primary and secondary research would be utilised.

3.6 Qualitative Research:

A key principle in the *Report of the Commission on the Status of People with a Disability (1996)* is that as a society we must maximise participation and enable independence and choice for people with disabilities. The Commission also states that people with disabilities have *"the right to influence decisions which affect their lives" and "they have the right to be able to make their own decisions and choices regarding the condition of life best suited to them"* (National Disability Authority). May (2011:131) contends that *"interviews yield rich insights into people's biographies, experiences, opinions, values, aspirations, attitudes and feelings".* Therefore it was important to the researcher that the participants of this study were clients as opposed to professionals.

Qualitative research is concerned with the study of *"things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them"* (Denzin & Lincoln, 1998:3). Bolte (2014:67) notes that *"the main objective of qualitative research is to gain a deeper understanding of human behaviour and experiences".* He also states that *"qualitative research helps to ask the right questions, derive hypotheses, and can enable a deeper understanding of certain processes in humans".* It is under-pinned by interpretive epistemology and constructionist ontology (Tuli,2011). In order to obtain rich and congruent data, it was essential therefore that the research would be qualitative from the client's perspective as opposed to quantitative or from the context of the professional.

3.7 Participatory Research:

This participatory research study is a collaborative project between the researcher and the Aspect service based at the CAA. Participatory research is based on the pragmatist philosophy of Paulo Freire who maintained that *"knowledge and action are both necessary for transformation to occur and argued for the right of everyone to be able to participate in the process of transformation". "It is underpinned by a strong belief that research should effect change" (Charles & Ward, 2007).* This method involves communities in the research to influence social change. It recognises that those involved are the experts in their own

narrative. Thompson(2009) states that as professionals we must ensure that our own method of practice does not promote oppressive practice. And the researcher would argue that in order for this study to be congruent and empower the participants, it was imperative that they were pivotal to the process.

3.8 Theoretical Perspective:

As the mother of a child with special needs and having previously worked as an advocate within the disability sector, the researcher's ontological position comes from a social constructionist perspective. Quin & Redmond (2003:85) state that *"a social model of disability requires change in the social world rather than in the people who inhabit it".* And more recently, Neilson & Heffernan, (2013) state that ASD is not necessarily a disability however it is the social demands and external factors which disable people who are different. A literature review by the National Disability Authority in 2007 highlighted that, "a *major reason for negative social attitudes, resulting in the denial of basic values and rights/conditions is the way disability is portrayed and interpreted in society" (NDA,2007:24).* Michael Oliver (2009) also argued that it is the social and environmental factors which are the barriers to participation and not the impairment. And Renty & Roeyers (2006:521) declared that *"the extent to which one is 'disabled' is the result less of factors residing in the individual and more of the interaction between the individual and the environment".* The UN Convention on the Rights of Persons with Disabilities is the first legally binding instrument which protects the rights of person with disabilities. *"The Convention adopts a social model of disability through its recognition that disability results from interaction between a non-inclusive society and individuals"* (Hamilton, 2011:219). Historically in society the terms "*disability*" and "*impairment*" were used interchangeably. However social constructionist theorists would argue that they are not synonyms of each other as impairment refers to biology, whereas disability occurs as a result of negative perceptions, misconceptions, incorrect use of language and environmental factors.

As the researcher and the CAA were aware of the negative connotations associated with the term disability, a collective decision was made that the focus of the interviews would not be on the term AS but rather on the challenges associated with the characteristics of AS. At the initial planning meeting the researcher and the CAA agreed that the term '*disabled'* would not be used in relation to the participants as this term might suggest that they were *'less able*'. The recent changes to the DSM 5 meant that people who were

previously diagnosed with AS could now be classified as having an autistic spectrum disorder. The researcher was very interested in hearing the participants' views on the social construction of these terms and the impact that these changes had upon them. However as this was not the focus of the study, the researcher decided that this topic would only be explored if the participants themselves raised the matter.

3.9 Choosing the Research Participants:

To circumvent possible ethical issues regarding the capacity of potential participants it was decided that purposive sampling would be used. Having consulted with the CAA and a member of the CARL committee, it was decided that Aspect would identify six adults as possible participants for this study. The participants who were chosen were all over aged 18. It was essential for this study that a random group would not be used as they would be unlikely to have a *"shared* perspective" (Morgan, 1996:35). And it was important that all of the participants had a shared experience and had something to say about it. The researcher interpreted the data using interpretative phenomenological analysis (IPA) as this method looks at the *"insider's perspective"* and attempts *"to explore how participants make sense of their personal world"* (Griffith et al, 2011: 534). Studies using this methodology generally feature five to ten participants. As a result the CAA and the researcher decided to invite ten participants to the focus group, however the final number was six. As Aspect the service provider was not the focus of this study, the researcher did not have any issues with bias in terms of the agency selecting suitable participants.

Whilst conducting the literature review, the researcher observed that there was a distinct lack of female participants. In order to be an authentic representation of the demographics of the Aspect service, the researcher decided that both males and females would be invited to partake in this study. Of the six that agreed to participate, three were female.

3.10 Gender imbalance:

In all of the literature a gender imbalance exists in terms of individuals with AS. The World Health Organisation report that the male to female ratio is 8:1. Many theories have been suggested as to why this imbalance exists, most notably by Simon Baron Cohen. He hypothesised that "*autism represents the phenotype of an extreme male brain"*
(Cohen 2004:820). Girls he suggests, *"begin to understand their world through empathising with others searching their faces attempting to identify another's mental*

status and respond to those with appropriate emotion. In order to predict and respond to the behaviour of another person". Boys on the other hand are described as using a more *"mechanistic approach to understanding their surroundings"* (ibid). He argues that the female brain is hard-wired for empathy whilst the male brain is hard-wired for understanding and building systems. The male dominance in this area could explain the paucity of the female perspective in the literature, however in order to reflect the current gender demographic of Aspect which consists of 75% males and 25% females, both males and females were included in this study.

3.11 Limitations:

a. Limitations regarding purposive sampling:

In order for this study to be a congruent representation of the experiences of people with AS, client participation was essential. However as the researcher would not have access to possible participants, the CAA and a member of the CARL project agreed that a member of the Aspect staff would identify suitable candidates. On the night of the focus group, six of the invited ten participants were in attendance. The researcher had no prior knowledge as to the reasons why these six agreed to participate and the remaining four did not. The topic may not have been of interest to them or conversely, difficulties with communication and social interaction may have deterred them. In the researcher's opinion, the six that participated were all able to articulate their experiences. However not all people with AS have these capabilities. Consequently, the researcher is aware that these sampling techniques may have limited this study.

b. Limitations of IPA:

Because it is only possible to do the detailed nuanced analysis associated with IPA with small samples of five to ten participants (Smith, 2004), the researcher recognises that these findings are not adequate to represent a larger population. May (2011:139) urges that *"caution should be exercised in attributing the opinions of such a group to whole populations".* As a result of time constraints only one focus group was possible. Therefore the researcher is aware that the findings of this study may not be representative of the experiences of all Aspect clients. Morgan (1996:44) notes that *"The problem with having only one group is that it is impossible to tell when the discussion reflects either the unusual composition of that group or the dynamics of that unique set of participants".* In order to apply the findings of this study to a more general population, the researcher recommends

that at least one more focus group with a different participant demographic should be facilitated.

Brocki & Weardon (2006:98) stated that the role of the researcher when using IPA is that of an interpreter. However different levels of interpretation can result in different findings. They argue that IPA is *"inevitably subjective"* as interpretation can be influenced by the participants' abilities to communicate their experiences and the researcher's own conceptions and perceptions. The researcher is aware that as she has an interest in the area of disability and independent living, she was very passionate in her approach to this study. Although she endeavoured to remain completely impartial, she is aware that by using IPA it is impossible to remain completely objective (Smith, 2004). Whilst qualitative research itself also has limitations. May (2001:127) argues that it is *"difficult to create the right environment to gain qualitative data whilst also being detached and objective".*

3.12 Conclusions:

In this chapter the researcher explained the rationale for the design of the research instrument. From the researcher's perspective, client participation was pivotal to this study. However the researcher was aware that for ethical reasons she may have been unable to access participants for the focus group. In order to circumvent this the CAA and the researcher agreed that purposive sampling would be necessary. To ensure that this process did not make the participants anxious, they were given a questionnaire which they had the option of filling out before or after the focus group. The rationale for this was to provide them with insight as to what would be asked of them on the night. As result of the gender imbalance in the studies of adults with AS, the researcher decided that the focus group would consist of males and female. This balanced demographic is also more reflective of the Aspect client base. To conclude this chapter the researcher discussed the limitations of this study and the fact that the findings discussed in the next chapter cannot be applied to a general population.

Chapter Four
Findings and Analysis

"Can't you see I just want to have a friend
Can't you see I need the same connections in the end
Can't you see I want a good job

Can't you see I need to have stability and dependence
and part of the general mob
Can't you see I want to be independent on my own
Can't you see I want to be able to have my own home
Can't you see I want the same things as everyone else
Can't you see I want to be appreciated for myself"
(Scott Lentine, 2014)

4.1 Introduction:

In this chapter the researcher will discuss the primary research findings from the focus group of six participants and the information provided by four of them via a questionnaire. Four main themes emerged from the analysis. In accordance with IPA methodology, these themes were discussed from the group perspective as a whole. All narratives are presented verbatim.

4.2 Data analysis:

The focus group was recorded using a Dictaphone and the interviews were fully transcribed verbatim. Once transcribed, the interviews were listened to several times to enable the researcher to document relevant pauses, intonation and the questions which the participants struggled to answer. The themes of each section were recorded in the margin for the purposes of identifying emerging themes. Once recorded, all of the themes were colour coded and transferred onto large sheets of paper. This provided the researcher with visual clues as to reoccurring themes and the connections between them. As the focus of this study was expressly on independent living, all other themes not relating to this subject matter were excluded during the analysis.

4.3 Methodology:

The researcher used interpretative phenomenological analysis (IPA), a form of qualitative approach to analysis the research data. IPA has three broad elements to it *"it represents an epistemological position, offers a set of guidelines for conducting research, and describes a corpus of empirical research"* (Smith,2004:40). *"It is phenomenological in its concern with individuals' perceptions of objects or events*". But it also recognises the role of the researcher in interpreting those experiences. By using IPA the researcher's aim was to "*explore in detail participants' personal lived experience and how participants make sense of that personal experience"* (ibid). Critics of IPA state that it may be only suitable for semi-structured one to one interviews. They argue that in a focus group one dominant voice could silence the other participants and the researcher may interpret this as a general consensus. But because the aim of the researcher was to explore the feelings and experiences of this group she decided to use this method of analysis. To address a possible dominance issue, the researcher noted some of the information from the questionnaires and used these as general prompts during moments of reticence.

Wilkinson (cited in Smith, 2004;52) suggests *"that in certain circumstances, it is even possible that the focus group will facilitate personal disclosure more than individual interviews"*. When listening back to the audio recording, the researcher noted that when a participant was talking about things that their mothers would say or do, several other participants would also interject with their own similar stories. The researcher believes that some of the participants would not have been as honest and forthcoming in an individual interview situation.

One of the key objectives of this research was to interview adults with AS in order to document their opinions and to make sense of their experiences regarding independent living. Using this method provided *an "insider perspective*" (Smith, 1996:264) and allowed the researcher sufficient flexibility "*to allow unanticipated topics or themes to emerge during analysis"* (Smith, 2004:43). The researcher despite having studied the literature on people with AS was conscious not to formulate definitive research and questionnaire questions based on this literature but instead constructed broad questions which allowed for open discussions and the construction of further research questions.

4.4 Overview of Key Findings:

Of the six participants in this study, four lived with family, one shared a house with friends, one lived on her own and the last participant shared a house during the week but stayed with family at the weekends.

Theme 1: Definition of independent living:

All of the six participants defined independent living as the ability to cook and clean for themselves, manage money and do their own laundry. Four of the six stated that it also included the ability to do these things for themselves even if they lived with family.

"Being able to do things around the house even if you don't live on your own".

"Being able to manage things on your own if the need arises, you may not be away from your own home but if you are able to do things around the place yourself without needing too much assistance"

The participants highlighted the importance of support from family and friends but did not wish to be viewed as *"dependent".* And only one of the six equated independent living with paying rent.

Theme 2: Barriers to independent living:

Three of the four participants who lived at home expressed a desire to live away from the family home. They all had positive experiences of living at home but felt that it was time to move out and to be able to do things for themselves. The only participant who said that she would prefer to remain at home was still in University and was concerned that she would become socially isolated if she did move out. All of the participants cited lack of finances as the greatest barrier to independent living,

"I haven't had a job in three years and its really annoying. I love living at home but I want to get out 'cause I have lived there all my life".

"finances.....that just comes first before everything".

Another barrier which the group highlighted was the fear of being bullied and feeling vulnerable. All of the participants spoke of previous experiences when they were bullied,

"I have seen the good, the bad and the really ugly of what it's like living with people. People can be really nasty. I was in one house and one girl was like so nasty....she was

bullying me into moving out".

Another stated that she tried living on her own for a while but got in with a bad crowd and had to return home. The male participants also experienced bullying, however unlike the females of the group, it would not deter them from sharing a house with another person.

Theme 3: Impact of AS characteristics upon independent living:

As previously discussed in chapter one, the researcher and the CAA had agreed that the characteristics of Asperger Syndrome would only be discussed in relation to independent living. No reference would be made to labels, diagnosis or the changes to the DSM 5. The researcher decided that if the participants raised this topic themselves then the impact of all of the above would be discussed. However as the group did not make any reference to these topics, the characteristics of AS were discussed solely in relation to the challenges of living independently.

a. Organisation and planning:

All of the participants cited varying degrees of difficulties in the area of planning and organisation. Whilst discussing the importance of lists and visual aids such as calendars and diaries to assist in this area, all of the participants admitted to using them at some stage but only one would use them on a daily basis and four only for important things like college lectures, assignment deadlines and Aspect meetings and one would not use them at all. All of the participants stated that other people telling them to make lists was a source of stress for them,

"my mother tells me you have to make lists. I say to her you have your way of doing things and I have mine. I have my own way of doing things".

"people would say you need to do it now and I'm like come on I said that I will do it in my own time, I do do those things you just haven't noticed them yourself"

Difficulty with time-management was another area that all of the participants highlighted,

"sometimes I'm good at timekeeping but sometimes I feel like I might get so many appointments that I can forget the times and dates of stuff and then it seems to build up and I get so stressed out".

"you're on a longer time schedule than everyone else you live with"

b. Domesticity and independent living:

All of the participants stated that they had varying degrees of competency in this area. Three of the participants lived out of home, albeit one did go home at the weekends. In relation to finances, all of the participants expressed that a lack of money was their greatest concern and five out of the six said that they can manage their money.

"working off the Euro 188 is a bit of a challenge. I can manage my budget well enough but stretching the Euro 188 can be a bit if a pain".

"I can pay my own bills and I know what goes in and out of my bank account".

Three of the six participants who were all still living at home expressed their frustrations with not being allowed to do things for themselves. They felt that even if you live at home you can still be independent if you can cook and grocery shop for yourself,

"Being able to do things around the house even if you don't live on your own". Being able to do your own laundry, cook your own food, keep yourself organised without somebody leaning over your shoulder to see how you done this and that".

When asked their experiences of cleaning, three of the participants had some difficulties in this area. However the researcher was unable to ascertain if this was as a result of apathy or an inability to manage this effectively,

"I tend to let cleaning things slide".

"my mother does all that".

"I can keep my side of the flat reasonably tidy, not by other people's standards but it's under control. It's ironic I have a touch of Asperger's and you would think that I would be super attentive to detail but I'm not".

c. Social challenges/ Theory of mind:

Based on the literature review, the researcher was aware that the theory of mind could have been the most difficult area for the participants to discuss. The challenge for the researcher was how to get the participants to discuss something which isn't tangible. To address this, the discussion started with social challenges and from there progressed to other peoples' intentions towards them. The researcher did not use the term theory of mind.

In terms of friendships all of the participants stated that they liked the idea of having friends but that they had varying degrees of difficulty in socialising and maintaining friendships. And there were many times when they would rather be on their own.

"I think that it is difficult for some people with AS to make and maintain friendships".

"unfortunately for me , I try to get along, make friends for as long as I can but lately the people I know have moved on and it's been a case of it's kind of hard to stay in touch with them"

"I love meeting people"

"You have to psych yourself up every day..... I know I have to deal with people but I don't want to but I have to"

On why a participant prefers to live alone *"I can't be coming home at night to put on an act to face those people".*

During the discussion on issues that arose in previous friendships, three of the participants stated that they had difficulties with inferred meanings and recognising the intentions of others,

"I'd click with anyone. I wouldn't see the bad in anyone, I'd always see the good in people".

Another said that she has "*a knack of not noticing whether people are genuine or not and I would not know that I'm being bullied.....I don't know whether they are good or bad".*

d. Stress/Depression/Anxiety:

Half way through the focus group one of the participants admitted to being stressed due to college work. The researcher asked her if she wanted to finish or to take a break but she said that she wished to remain. At this point the focus of the group shifted to things which stressed the participants. None of the participants stated that depression was an issue for them but they all said that being stressed could make them anxious.

"I get stressed when people are getting on at me about not being stressed enough about certain things"

"I have to go out now and meet people and deal with this.....it's kind of a huge stressor"

All of the participants stated that further education was very stressful for them. The three male participants had to repeat one or two years at University due to difficulties in understanding the curriculum and interacting with fellow students. Two of these students said that the idea of having to repeat again at the end of the year was very stressful for

them.

Five of the participants said that when family members, especially mothers watched over them when they were doing domestic tasks they became very stressed. They expressed a desire to do these things for themselves, their own way and in their own time frame

"*I might do things a little later than I should but I would end up doing things.....people would say you need to do it now and I'm like come on ….I said that I will do it in my own time"*

"being able to do your own laundry, cook your own food, keep yourself organised without somebody standing over your shoulder to see how you've done this and that"

"my mother"

Theme 4: Hopes for the future:

The final topic introduced at the end of the focus group was that of participants' hopes for the future. This topic was not featured on the questionnaire as the researcher had not planned to discuss this. However as the previous topic had resulted in some emotional narratives, the researcher wanted to ensure that the participants left the focus group feeling empowered and positive about their future prospects. The following is a list of the participants' aspirations. To preserve anonymity they are not listed in any specific order,

"Get a job in computer design and development. Save up money to have a place on my own, maybe a girlfriend".

"I'm looking for a job at the moment so that I can save up and move out over the summer.....I love living at home but I want to get out as I've been there all my life. I want to do National Park's Works in America. Finish my degree, save money, get a place to live, travel, meet people and take photographs of things that I like".

Important things for the future are *"career, living my life, my friends and my family".* Would like to change careers and try veterinary nursing.

"I hope to move out on my own, to be able to move out again.....maybe find a boyfriend 'cause I'm the last one in my family".

"Get a job in computer design and development. Save up enough money to have a place on my own ...maybe a girlfriend....I would love to find someone that I could click with".

"Finish the course that I'm on".

4.5 Reflexivity: the researcher's position:

The researcher is aware of the influence of her own experiences on this research. As a mother of a child with special needs she could understand the participants' frustrations in

relation to independence however she could also understand the parents' need to protect. The researcher has also had some negative experiences with the dominance of the medical model and the professionals' need to diagnose, label and categorise human beings in order to provide them with a service. The researcher hoped that her social work training and the guidance from her tutors has helped her to be as objective as was necessary to accurately reflect the participants' narrative.

4.6 Conclusion:

In this chapter the researcher presented the findings from the primary research. The data was analysed using IPA as this method concerns itself with the feelings and the experiences of the participants and explores how they make sense of those experiences.

All of the participants stated that regardless as to whether they lived on their own or with family/friends, they wanted to to cook and clean for themselves. They outlined their frustrations when other people especially mothers would supervise them. However they acknowledged that support was important to them. All of the participants stated that the greatest barrier to independent living was a lack of finances. And four of the six participants had had previous negative experiences of sharing houses with other people other than family. In the next chapter the researcher discussed her recommendations. It was important to the researcher that these recommendations would be practicable and purposeful. And that they would be based on feedback from the participants as opposed to the researcher's conceptions.

Chapter Five

Recommendations and Conclusions

" Who I was, is who I am. For who I was, will always be within
Passion, determination and resilience, the many trials of life weaken me
My lack of understanding customs and rules, these are my faults
External misunderstandings give me strength, I fall from grace in who I am
Never will I lay down for long. Binding me will only make me struggle harder
Who am I, I am me ". (Getty, N., 2014).

5.1 Introduction:

In this chapter the researcher will present her recommendations based on the themes discussed previously. When considering possible interventions to promote independent living for people with AS whether they were living on their own or with family, it was important to the researcher that the recommendations would be practicable, cost effective, ideally with minimal cost and would have short term feasibly.

5.2 Recommendations:

Recommendation one: Independent living skills module/Assisted Daily Living

Five of the participants stated that they would prefer to shop for their own groceries, cook, clean and do their laundry regardless as to whether they lived with family or on their own. At present when an individual engages with Aspect depending on their individual goals, they can receive instruction in money management, healthy cooking and budgeting on a one to one basis. The researcher believes that a module such as Occupational Therapy's Assisted Daily Living could benefit Aspect clients. This person-centred module would be based on an individual assessment of needs. A report by the National Autistic Society highlighted that *"some-one may know how to look after himself but not actually do it, as knowing facts about independent living and being able to live independently are two distinct things for some-one with an ASD"* (National Autistic Society, 2007:66). The

researcher envisages that this module would incorporate practical and theoretical facets and would link several aspects together depending on the client's ability. For example the client would be supported to devise a meal that he would cook for himself. This task would involve deciding on which recipe to cook, devising a list of ingredients, calculating the cost, preparation and cooking of the ingredients and would also factor in the fire safety and food safety aspect. Depending on the client's assessment of needs, this module could also include doing the laundry, ironing and cleaning.

Recommendation two: Transitional Workshops for Parents

When discussing cooking and cleaning, the participants highlighted their frustrations when people would "*look over their shoulders and watch them when they did do these things"*. All of the participants stated that it was usually their mothers who would do this, *"I say to my mother.....I have my way of doing things and you have yours"*. As a mother of a child with special needs, the researcher can empathise with these mothers. When the natural instinct is to protect a vulnerable individual, it can be very difficult to allow them to do these things for themselves. However if a client learns these skills when in Aspect and then is not encouraged to do them at home, the researcher would contend that they are then denied the opportunity for growth and are dis-empowered. The researcher would recommend the facilitation of a workshop for parents within Aspect to run in tandem with the assisted living training. The rationale for this workshop would be to outline to the parents the structure of the assisted living training and also to explain the importance of fade away supports.

Recommendation three: Independent living advocate

Four of the six participants were either living on their own now or had done so previously. All of them stated that they had had negative experiences with room mates, landlords or were unsure of what to do when an appliance broke. Two of the participants said that because of their age they did not want to seek help from their parents. At present the individual key workers provide assistance in this area. However the researcher recommends that Aspect should appoint an Independent Living Advocate. This Advocate would provide assistance with finding accommodation, negotiating with landlords, rent allowance applications and linking suitable Aspect clients together as potential room mates. The key workers would still have responsibility for the more domestic aspects of

independent living and the clients would have the security of knowing that they have access to supports other than family.

Additional future recommendation: Aspect supported housing

As Aspect do not provide any supported housing services at present apart from linking with housing agencies and the Department of Social Protection, the researcher believes that the concept of Aspect supported housing could be a topic for another CARL research project.

Willow House opened in Norton in the UK in January 2014. This development consisted of five one bedroom apartments for individuals with an ASD. This project was a joint venture between Curo, Bath and North East Somerset Council's Learning Difficulties Team and the National Autistic Society. The aim was to provide safe, quality, affordable and supported accommodation so that individuals could live independently but still near to their families (Willow House 2014).

The National Autistic Society highlighted that,*"people with Asperger Syndrome often thrive in supported environments, and they do so because they are helped by structure and support"* (National Autistic Society, 2007:52). The researcher believes that this type of supported housing could also be used as a transitional stage for those who would wish to live on their own whilst still being supported.

5.3 Implications for social work practice:

Maslow (1943) argued that in order for a person to reach a stage of self-actualisation, their independence must be promoted and also they must be afforded the opportunity to make decisions for themselves. And furthermore that this process involves what he referred to as *dignity of risk*. This dignity of risk can be defined as *"respecting each individual's autonomy and self-determination to make choices for himself or herself. Even if healthcare professionals believe their choices endanger the person's health or longevity"* (Disability Practice Institute, 2014). Dejong(1979) cited in (Quin & Redmond, 2003:77) referred to the possibility of risk and failure for a person with disabilities when living independently. He argued that without the possibility of failure, *"the disabled person is said to lack true independence and the mark of one's humanity is the right to choose between good and*

evil". The researcher would argue that as professionals unless we empower and support individuals with AS to live as independently as possible, we continue to '*disable'* them. Because of the dominance of the medical and the fear of litigation many professionals consider the family home or a congregated setting the only safe option for a person with a disability. But the researcher contends that we must provide the necessary supports to enable an individual with AS to take risks and make mistakes, otherwise we promote the concept of '*learned helplessness'.*

Seligman (*1975)* introduced the concept of '*learned helplessness'.* He argued that the more a person is protected and sheltered under the guise of not being able to take care of themselves, the more dependent they become. This learned helplessness could create a greater reliance on family and the State for supports other than financial. The researcher would argue that this over-reliance on supports could create further social isolation. Although they do not live in an institution they essentially could become '*institutionalised'.*

5.4 Author's Reflections:

Just under a year ago I began this project. Daunted by the prospect of having to write a dissertation, I decided to do a CARL project as I recognised the importance of having as much support as possible. My own personal experience is in the area of Autism and the associated challenges. However I as I had limited knowledge of Asperger Syndrome I chose this project. From the beginning the team at Aspect and The Cork Association for Autism embraced this project. As a social work student and an advocate for people with a disability it was important to me that this project concerned the experiences of the client as opposed to the professional. I believe that for too long there has been an absence of the client perspective and would argue that whilst professionals may have knowledge of a particular area, they are not the experts. Without Aspect I would not have had access to the participants and I am grateful to them for the opportunity to meet with their clients.

Regarding the clients themselves, I am indebted to them for their honesty, their humour, their time and their support. During the focus group they supported each other and despite the lack of theory of mind which is generally associated with AS, they offered unsolicited advice and words of encouragement to each other throughout the focus group. When we discussed the issue of bullying and vulnerability, I was very angry to think that as a society we are constantly developing new ways of enforcing that some people are *'less than'*.

When I listened to the recordings I realised the participants would have discussed this topic further but I changed the subject. Clearly some truths are just too real to listen to. However the participants' hopes for the future inspired me, all they want is to work, travel, be happy and be loved: just like the rest of us.

5.5 Conclusions:

This CARL research study was a collaborative project between the researcher and the AS Aspect service of the Cork Association for Autism. The aim of this research was to explore the experiences of adults with Asperger Syndrome/High-functioning autism in relation to independent living. In order to achieve the aims and objectives of this study, the researcher used primary and secondary research. The focus group of six ASPECT clients highlighted that a person can live with family and still be independent if they are given the opportunity to cook and clean for themselves and manage their own money. For those who wished to live outside of the family home, they stated that the greatest barrier is lack of finances.

Having analysed the data the researcher made the following recommendations;

- The introduction of an Independent living skills/Assisted daily living module.
- An Independence Transitional Workshop for parents to support the above.
- The recruitment of an Aspect Independent Living Advocate.

The researcher would also suggest that the concept of Aspect supported housing should be explored as the next CAA/CARL project. Finally the researcher hopes that the honesty, humour, integrity and determination of these participants will inspire and inform all those who will read this research study.

Bibliography:

American Psychiatric Association (2013). Available at: www.psychiatry.org.
[Accessed on 14/02/2014].

Aristotle. (1797) Aristotle's Ethics and Politics, Comprising his practical philosophy, translated from the Greek. Illustrated by introductions and notes: the critical history of his life: and a new analysis of his speculative works by John Giles,...In Two Volumes.
Vol. Volume 1. London,1791.
Eighteenth Century Collections on line. Gale. University College Cork.
Available at : <http://0-find.galegroup.com.library.ucc.ie/ecco/infomark.do?&source=gale&podid=ECCO&userGroupName=uccork&tabID=Tool&dodd=CW122398632&type=multipage&contentSet=ECCOArticles&version=1.0&docLevel-Fascilimes>
[Accessed on 14/04/2014].

Aspect (2013). Available at www.corkautism.ie/aspect**.** [Accessed on multiple dates].

Attwood, T. (2007) *The Complete Guide to Asperger Syndrome.* Tyne and Wear: Athenaeum Press.

Autism Speaks(2014). Available at www.autismspeaks.org/family.../tool/.../asperger/.../executivening-functioning.
[Accessed on 23/04/2014].

Bollard, G. (2013) 'Playing it Safe, Taking Risks, Nagging and Change', *Living with Aspergers,*12/31/2013. Available at: **life-with-aspergers**.blogspot.com/.
[Accessed on 25/04/2014].

Bollard, G. (2007) 'Depression and Anxiety', *Living with Aspergers,*11/23/2007. Available at: **life-with-aspergers**.blogspot.com/. [Accessed on 245/04/2014].

Bolte, S. (2014) ' The power of words: Is qualitative research as important as quantitative research in the study of autism?'. *Autism*, 2014 18:67. Available online at:

http://aut.sagepub.com/content/18/2/67. [Accessed on 15/03/2014].
CARL (2013) Available at www.ucc.ie/en/sciship. [Accessed on multiple dates].

Charles, L., & Ward, N. (2007) *Generating Change through Research: Action Research and Its Implications.* Newcastle Upon Tyne: Centre for Rural Economy. University of Newcastle Upon Tyne. Available at: www.ncl.ac.uk/cre/publish/discussionpapers/pdfs/dp10.pdf. [Accessed on 26/04/2014].

Cohen, S. B.(2004) *The Essential Difference: Men, Women and the Extreme Male Brain.* New York: Penguin Books.

Cork Association for Autism (2013). Available at: www.corkautism.ie.
[Accessed on multiple dates].

Council of Europe(2008) The Chapter of Fundamental Rights of the European Union. Available at: www.coe.int/t/ngo/Source/reading_reading_guide_charter_en.pdf.
[Accessed on 25/03/2014].

Denzin,A.K. & Lincoln, Y.S. (1998) 'Introduction: Entering the Field of Qualitative Research' in Denzin, A.K. & Lincoln,Y.S. (eds) *Strategies of Qualitative Inquiry. London*: Sage Publications Ltd.

Getty, N. (2014). Available at:www.aspergerrus.com/my-poems-and-writings.html.
[Accessed on 25/04/2014].

Good, S., Howlin, P. & Rutter, M. (1999) 'A Cognitive and Behavioural Study of Outcomes in Young Adults with Autism'. *Autism,* March:63-83. Available online at: www.aut.sagepub.com/content/4/1/63. [Accessed on 25/03/2014].

Government of Ireland. 1999. National Disability Authority Act 1999. Available online at: www.irishstatutebook.ie/1999/en/act/pub/0014/index.html. [Accessed on multiple dates].

Government of Ireland. 2006. *Towards 2016 Ten-Year Framework Social Partnership Agreement 2006-2015*. Dublin: Stationary Office. Available at:

http://www.taoiseach.gov.ie/attached_files/Pdf%20files/Towards2016PartnershipAgreement.pdf. [Accessed 10/02/2014].

Government of Ireland(2012). Autism Bill 2012. Available online at: www.oireachtas.ie>Bills 1992-2014. [Accessed on 10/01/2014].

Hamilton, C. (2011) *Irish Social Work Social Care Law.* Dublin: Gill & Macmillan.

Health Service Executive (2012) *National Review of Autism Services Past, Present and Way Forward.* Available online at: www.fedvol.ie_fileupload/Next. [Accessed on 16/12/2013].

Heffernan, D. & Neilson, S.(2013) *Living With Asperger Syndrome & Autism in Ireland.* Charleston:Neilson & Heffernan.

Henninger, N.A.,& Lounds Taylor, J. (2013) ' Outcomes in adults with autism spectrum disorders: a historical perspective'. *Autism 2013*, 17:103. Available online at: http://aut.sagepub.com/content/17/1/103]. [Accessed on 15/03/2014].

Howlin, P., Mawhood, L. & Rutter, M. (2000) 'Autism and Developmental Receptive Language Disorder-A Follow Up Comparison in Early Adult: Social, Behavioural and Psychiatric Outcomes', *Journal of Child Psychology and Psychiatry.*

Howlin, P., et al.(2004) ' Adult outcome for childrenwith autism'. *Journal of Child Psychology and Psychiatry* 45:2 (2004), pp 212–229.

Howlin, P. (2000) 'Outcomes in Adult Life for More Able Individuals with Autism or Asperger Syndrome' , *Autism 4* (1):63-83.

(ICESRC) The International Covenant on Economic Social and Cultural Rights(1976). Available online at:www.ohchr.org. [Accessed on 10/01/2014].

Irish Society for Autism (2014). Available online at: www.autism.ie. [Accessed on 15/04/2014].

Kite, D.M, et al.(2013) ' Views on the Diagnostic Labels of Autism and Asperger's Disorder and the Proposed Changes in the DSM', *Journal of Autism Development Disorder,*43:1692-1700.

Lentine, S. (2014). Available at: www.tonyattwood.com.au/. [Accessed on 25/04/2014].

Maslow, A. H.(1943). A theory of human motivation. *Psychological Review, 50*(4), 370–96.

Mesibov, G. B. et al.(2001) *Understanding Asperger Syndrome and High Functioning Autism.* New York: Kluwer Academic/Plenum Publishers.

Morgan, D. L. (1996) Focus Groups as Qualitative Research. Portland: Sage Publications Inc.

National Disability Authority(2014). Available online at: www.nda.ie/.
[Accessed on multiple dates].

National Disability *Authority(2007)* 'Literature Review on Attitudes Towards Disability. Dublin: National Disability Authority. Available online at: www.nda.ie/.../$File/Literature **Review**.pdf . [Accessed on 10/03/2014].

National Disability Authority(1996) *The Report of the Commission on the Status of People with Disabilities. A Strategy for Equality.* Available online at;www.nda.ie.>Home>Policy>PolicyPublications. [Accessed on 12/03/2014].

Neilson, S. & Heffernan, D.(2013) *Living With Asperger Syndrome & Autism in Ireland.* Charleston: Neilson & Heffernan.

Oliver, M. (2009) *Understanding Disability. From Theory to Practice*. Hampshire: Palgrave Macmillan.

Quin, S. & Redmond, B. (2003) *Disability & Social Policy in Ireland.* Dublin: University College Dublin Press.

Renty, J.O., & Roeyers, H. (2006) ' Quality of life in high-functioning adults with autism spectrum disorder- The predictive value of disability and support characteristics'. *Autism,* vol 10(5):511-524. Available online at: http:aut.sagepub.com/content/10/5/511. [Accessed on 15/03/2014].

Seidman, I. (2013) *Interviewing as Qualitative Research.* New York: Teachers' College Press.

Smith,B.M., & Southwick, J. (2005) *Asperger Syndrome and Difficult Moments.* Kansas: Autism Asperger Publishing Co.

Smith, J.A. (1994) 'Beyond the Divide Between Cognition And Discourse: Using Interpretative Phenomenological Analysis In Health Psychology', *Psychology and Health,*vol 11:261-271.

Smith, J.A. (2004) 'Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology, *Qualitative Research in Psychology,*1:39-54.

The International Covenant on Economic Social and Cultural Rights(1976). Available online at:www.ohchr.org. [Accessed on 10/01/2014].

The National Autistic Society(2014). Available online at: www.autism.org.uk**.** [Accessed on multiple dates].

Tickle, A., & Stott, B. (2010) *Exploring Bullying with Adults with Autism and Asperger's Syndrome. London*:Jessica Kingsley Publisher.

Thompson, N. (2009) *Understanding Social Work.* Hampshire: Palgrave Macmillan.

Tuli, F. (2011) 'The Basis of Distinction Between Qualitative and Quantitative Research in Social Sciences: Reflection on Ontological Epistemological and Methodological Perspectives'. *Journal of Education and Science,*vol 6, no.1:97-108.

UCC Code of Ethics. Available at www.ucc.ie/research/rio/ethics.html.
[Accessed on multiple dates].

UN Convention on the Rights of the Persons with Disabilities(2006). Available online at: www.un.org/disabilities/convention/conventionfull.shtml

Van Heijst, B.F.C., & Geurts, H.M. (2014) 'Quality of life in autism across the lifespan: A meta-analysis'. *Autism,* 1-10. Available online at: http://aut.sagepub.com/content/early/2014/01/16/1362361313517053.
[Accessed on 15/03/2014].

www.dsm5.org/.../Autism%20Spectrum%20Disorder%20Fact%20Sheet.
[Accessed on 10/02/2014].

World Health Organisation. Available at: www.who.int/iris/bitstream/10665/103312/1/978241506618_eng.pdf-260k.
[Accessed on 11/03/2014].

Appendix 1: What is Asperger's Syndrome / High Functioning Autism?

The umbrella term 'Autism Spectrum Disorder'(ASD) covers conditions such as Autism. Childhood Dis-integrative Disorder and Asperger's Syndrome. These disorders are a group of complex brain development disorders. They are characterised by difficulties in social interaction and the communication and a restricted and repetitive repertoire if interests and activities. ASDs are a group of complex brain development disorders. 50% of people with an ASD also have an intellectual disability(World Health Organisation, 2014a). Global research figures suggest that at present one child in 160 has an ASD(World Health Organisation, 2014b).

Asperger's Syndrome was first discovered in 1944 by Dr. Hans Asperger. He observed that some children displayed the typical characteristics of autism but their Intelligence Quotient was within the average range. The term *High Functioning Autism* was first used in 1981. This term has been used to describe children who displayed the stereotypical autistic characteristics but had greater intellectual ability that those diagnosed with traditional autism. Their cognitive abilities were also similar to that of children with AS(Attwood, 2007).

Tony Attwood(2007,:105) identified the following as the typical areas of difficulty for a person with AS;

- A person with AS may also present with Attention Deficit Hyperactivity Disorder.
- They often have language delays which resemble Semantic Pragmatic Language Disorder(SPLD) i.e: they will have good skills in the area of syntax, vocabulary and phonology, but poor use of language in a social context.
- Often they will have difficulties with co-ordination and dexterity and may be clumsy in gait.
- They may be sensitive to specific sounds, aromas, textures or touch.
- Delayed social maturity and social reasoning.
- Immature empathy.
- Difficulty making friends and are often teased by other children.

- Difficulty with communication and control of emotions.
- Unusual language abilities that include advanced vocabulary and syntax but delayed prosody and a tendency to be pedantic.
- May be fascinated with a topic that is unusual in intensity or focus.
- May have difficulties in maintaining attention in class.
- An unusual profile of learning abilities.
- A need for assistance with some self-help and organisational skills.

Appendix 2: An Overview of the Cork Association for Autism and Aspect.

The Cork Association for Autism was founded by a group of parents in 1978. They provide a range of services for approx 140 adults with Asperger's Syndrome and Autism in the Cork/Kerry region. Based in Greenville house, Carraigtwohill, services provided include, day services, respite services, home supports and outreach supports. In 2007 they launched their outreach support services for people with Asperger's Syndrome- Aspect .

“Aspect is a support service developed specifically for adults with Asperger Syndrome/ High Functioning Autism. A.S. is a spectrum condition which can present in many different ways and to varying degrees. It commonly effects social communication, social interaction, social imagination and sensory processing.

Characteristics of A.S. can vary from person to person and as with everyone, personal patterns and challenges alter and develop with experience and maturity. Because of this, the key workers at Aspect strive to provide a wide range of services to best suit their client’s needs. Aspect clients liaise with qualified and experienced key workers who help provide information and guidance in the areas of:

- education
- employment
- independent living skills
- communication and social skills
- sensory sensitivities
- social and community involvement
- leisure and recreation

Those engaging also have access to various Aspect services and groups that are facilitated by the team. These services include:

- counselling

- social/communication skills training
- training courses, workshops, seminars
- sensory integration interventions
- social groups
- regular social outings
- leisure and outdoor activities
- client and relatives support meetings

Links with housing authorities, local universities, employment agencies, etc. have been established by key workers to provide well informed and productive advice. There are also supports for relatives through Group Meetings which provide access to information and guest speakers with expertise in related areas

(Cork Association for Autism (2013).

Further information on the Cork Association for Autism and Aspect is available at: www.corkautism.ie.

Appendix 3: Changes to the DSM 5:

The primary manual used by clinicians to diagnose AS is the Diagnostic and Statistical Manual (DSM) from the American Psychiatric Association (APA) and the ICD 110 from the World Health Organisation (WHO). *"One of the most important changes in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is to autism spectrum disorder (ASD). The revised diagnosis represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders.*

Using DSM 5, patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood dis-integrative disorder, or the catch-all diagnosis of pervasive developmental disorder not otherwise specified. Researchers found that these separate diagnoses were not consistently applied across different clinics and treatment centres. Anyone diagnosed with one of the four pervasive developmental disorders (PDD) from DSM-IV should still meet the criteria for ASD in DSM-5 or another, more accurate DSM-5 diagnosis. While DSM does not outline recommended treatment and services for mental disorders, determining an accurate diagnosis is a first step for a clinician in defining a treatment plan for a patient.

People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading non-verbal interactions, or having difficulty building friendships appropriate to their age. In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. Again, the symptoms of people with ASD will fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms. This spectrum will allow clinicians to account for the variations in symptoms and behaviours from person to person.

Under the DSM-5 criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later. This criteria change encourages earlier diagnosis of ASD but also allows people whose symptoms may not be

fully recognized until social demands exceed their capacity to receive the diagnosis. It is an important change from DSM 4 criteria, which was geared toward identifying school-aged children with autism-related disorders, but not as useful in diagnosing younger children".

(American Psychiatric Association, 2013).

Appendix 4: Letter for Agency Contact Person:

25/08/2013.

Dear Joe,

following on from our discussions at last week's meeting, please find attached a letter for the Board of Management regarding the proposed research study. Do not hesitate to contact me if you have any further queries,

Regards,
Gillian Coogan.

25/08/2013.

Board of Management,
Cork Association for Autism.

To whom it may concern,

my name is Gillian Coogan and I am a final year social work student in University College Cork. As part of my degree I have to conduct research for a dissertation. My dissertation title is "*An Exploration of the Views of Individuals with Asperger's Syndrome/High-Functioning Autism.* This dissertation is part of the CARL project which your agency is involved with. As discussed with Joe Mc Donnell, I will be interviewing some Aspect clients as part of a focus group. The finished research study will be published on the CARL website and will also be read by my tutor, external examiners and other student. However all information will be anonymised. All recordings will be transcribed verbatim, but will remain confidential, will be stored safely and will be destroyed six months after publication. No identifying details will be used. All participants will be sent an information pack from me prior to the interviews and they are free to withdraw their consent at any stage.

I hope that this answers all of your questions and please feel free to contact me should you require any further clarification,

Regards,
Gillian Coogan.

Appendix 5: Introductory Letter for Participants:

To whom it may concern,

My Name is Gillian Coogan and I am a final year Bachelor of Social Work student attending University College Cork. I am undertaking a thesis in conjunction with the Cork Association for Autism/Aspect. The title of this research project is *An Exploration of the Views of Adults with Asperger's Syndrome in Relation to Independent Living* . On completion of this project I will endeavour to ensure that the results are a true reflection of the participants' opinions and I would hope that the findings once published will inform future policy decisions.

I am proposing to interview six Aspect clients in a focus group setting. All information used will be anonymised and all research material will be stored safely and destroyed six months after publication of the report. I have enclosed some information for you to read regarding the focus group format and consent forms. I would appreciate your assistance with this research project and I look forward to hearing from you,

Regards,

Gillian Coogan.
Tel: xxxxxxxx
Email: xxxxxx

Appendix 6: Information Sheet For Participants:

Purpose of the study: As part of the requirements for Bachelor of Social Work(BSW), I have to carry out a research study. The study is concerned with exploring the views of adults with Asperger Syndrome in relation to independent living on behalf of the Cork Association for Autism and University College Cork CARL Project.

What is required from participants? Participants will be required to fill out the enclosed questionnaire and attend an interview at 5pm on Wednesday 26th of February 2014 in the meeting room 73 Penrose Warf.

What is the structure of the interview? The interview will consist of a focus group of six adults which will last for forty five minutes. Participants will be asked to speak on their opinions/experiences regarding Independent living.

Why have you been asked to take part? You have been asked to take part because you have personal insight which may inform this research.

Do you have to take part? Taking part is voluntary, you will be asked to give your consent for interview and use of information in the final report.

Will your participation in the study be kept confidential? It will be confidential in that I will not share your personal details with anyone else. Sample quotes will be used in the final report but these will be anonymous.

What will happen to the information which you give? The information collected will be kept confidential from others, including college staff and community organisations(CAA) for the duration of the study. Names and other personal details will not be shared or published. All recordings and transcribed interviews will be stored safely and destroyed 6 months after the project is completed.

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 examination board. The thesis may be read by future students. The study will be published on the internet in conjunction with Community Academic-Research Links(CARL) and UCC. It will also be presented to the Cork Association for Autism.

What are the possible disadvantages of taking part? I do not envisage any negative consequences for you in taking part. However, it is possible that talking about your experiences may cause you some distress.

What if there is a problem? At the end of the interview I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed Yvonne Scriven from Aspect (CAA) will be on hand to provide support.

Who has reviewed this study? This study has been reviewed by my supervisor, CARL committee and the Cork Association for Autism. Ethical consideration has been given to all aspects of this study.

Any further queries? Contact: Email: xxxxxxxxx or tel: xxxxxxxxxx

Appendix 7: Questionnaires for Participants.

Name: ……..

Age: ……..

Are you (tick one):

In full-time education.....

In full-time employment.....

In part-time employment.....

Unemployed ……..

What is your marital status: .....

Who do you live with:

Parents.....

Spouse.....

Partner.....

Sibling.....

Friend.....

Other.....

Is this your preferred option: …….....

If not please state what your preference would be ……..

……

How would you define '*independent living*' .....

….....

….....

Do you consider yourself to be living independently.....

….....

Do you have difficulties in any of the following areas:

1. Social Settings.....

2. Making and Sustaining Friendships.....

3.Organisation and Planning.....

4. Rigid Thinking or Inflexibility.....

5. Communication.....

6. Money Management.....

7. Sharing a living space with another person.....

8. Sensory issues.....

If yes how do the difficulties impact upon your current living arrangements.....

….....

….....

….....

….....

….....

What do you see as the greatest barrier to a person with Asperger Syndrome in living independently:

…….

…….

…….

…….

…….

Any additional comments:

…….

…….

…….

…….

…….

Thank you

Gillian Coogan.

Tel: xxxxxxxxxxx
Email:xxxxxxxx

Appendix 8: Participants' Consent Agreement:

I.....agree to participate in Gillian Coogan's research study on behalf of CAA/ UCC CARL Project.

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

I am participating voluntarily.

If I have any questions about this study, I am free to contact Gillian Coogan.

I give permission for my interview with Gillian Coogan to be recorded.

I am aware that I may stop the interview at any stage or withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that my anonymity will be ensured throughout this process.

I am aware that the recording of the interview will be transcribed. This transcript will be stored safely and destroyed 6 months after the project is completed.

I understand that disguised extracts from my interview may be quoted in a thesis if I give permission below. This will also be seen by UCC staff, external examiners and will be published on the CARL website. It may also be read by future students.

(Please tick one:)

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

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

Signed.....

Date.....

Thank you

Gillian Coogan

Contact details: Tel: xxxxxxxxx
Email: xxxxxxxxxx