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UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

An Exploration of the Supports Needed for Students with Asperger's Syndrome to Successfully Complete Third Level Education.

Sinead Slattery

CARL Research Project

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Name of civil society organization/community group:	National Learning Network
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Name and year of course:	MSocSc in Third Sector Management 2012
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- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
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Abstract

This study is concerned with looking at the supports required for students with Asperger's Syndrome to successfully transition to third level education. It is a participatory research project in collaboration with the National Learning Network. The organisation proposes developing a pre college transition programme for students with Asperger's Syndrome to run for an academic year prior to commencing a place in third level education. This research aims to support the development of this programme by establishing a need for it and subsequently determining areas which are critical to be included. In order to meet these research aims, the research uses two strategies; 1) an analysis of relevant literature and 2) qualitative interviews with third level students who have a diagnosis of Asperger's Syndrome.

The literature provides a legislative context, international case studies and best practise guidelines for the proposed programme. The qualitative interviews offer descriptions of the lived experiences of third level education for students with Asperger's Syndrome. The findings and conclusions from the literature and the qualitative accounts establish a need for the programme and identify supports which are necessary to be incorporated into it. Consequently, these conclusions culminate in recommendations to the National Learning Network in order for them to develop a programme of support which is appropriate to the identified needs of the students.

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http://carl.ucc.ie

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Executive Summary

Background to the study

The National Learning Network (hereafter NLN) is one of the leading providers of training and specialist support to people with disabilities in Ireland. For over 50 years the organisation has worked in the area of disability and training for employment or further education. The ethos of a person-centered approach to service provision is at the heart of everything the organisation does and this is reflected in Individual Action Plans where each learner is central to the process and to the services provided.

The organisation has identified a gap in support service provision for students with Asperger's Syndrome (hereafter AS) whilst they make the transition from second to third level education. Consequently, the organisation proposes to develop a pre college programme to target this.

The UCC Science Shop provides participatory research to a community organisation by allocating students to undertake a research project based on a specific topic identified by the organisation. The NLN sought the support of the UCC Science Shop in order to research the specific needs of students with AS in third level education. In line with their person centered ethos, it was imperative for them that action research was carried out to get the views of students with a diagnosis of AS who have had experience in third level. It is envisioned that if the programme is developed, the content will be primarily based upon the supports which the students have themselves identified through this research.

Objectives

The main objective of this research, which was decided in collaboration between the researcher and the NLN is to;

- Interview students with AS in UCC to gain insight into the lived experiences of their education and consequently identify supports which are essential for them to achieve their potential
- Formulate recommendations guided by the literature and the qualitative research and provide them to the NLN with the view of them using them to develop a targeted pre college programme for students with AS.

Methodology

A qualitative and participatory method of research was employed to conduct the research underpinned with an interpretive approach. A comprehensive literature review was undertaken and 8 semi structured interviews were completed. A purposive sampling technique was utilised to access students with a diagnosis of AS.

Findings

Evaluation of the legislation and policy regarding education of a person with a disability determines that there is a basis in law for all students to be given the opportunity to develop to their educational potential without discrimination.

The findings from both the literature review and the qualitative research found that students with AS have significant difficulties in third level education. There is considerable support in the literature and from the student experiences to endorse establishment of a pre college programme for students with AS.

In interviewing the students a number of significant issues were highlighted. The need for assistance and support in areas such as transitioning, social skills, organisational skills, motivation and study skills are all identified throughout the research and culminate in recommendations made to the NLN.

Recommendations and Implications of the study's findings

Recommendations arising from this research are being made to the NLN with the purpose of developing a programme with an agenda which has been developed by the students.

It is envisioned that they can be utilised in the establishment of a pre college programme. The recommendations are based primarily on the information provided by the students, supported by the literature. Below is a summary of the main recommendations.

1) The research suggests that there is an apparent need for this programme and that in general there is positive feedback from students with AS about the merits of participating in it. Evidence from the research confirms that it is only with retrospective observation that the full benefits of this proposed programme become apparent.

Parental support was highlighted on many occasions and in many contexts as being essential to the student. The consensus from the interviewees was that there would need to be parental

support for the programme, as generally the main burden of extra cost would fall on them. The researcher deduces that the views of parents may influence the take up rate of the programme.

2) One of the main themes emerging from the narratives is that students struggled with organisational skills. Students mentioned that this led them to having difficulties with assignments and deadlines as they struggled to manage their time and workload. In order to effectively teach skills to allocate work based on deadlines and in order of importance it is suggested an actual academic module should be part of the pre college programme.
By completing one module it will allow students to go to lectures, interact with fellow students, complete assignments and get a pragmatic view of college life. This practical experience will allow them to self identify problems which emerge and help the NLN programme to identify individual needs. A person with AS can find it difficult to imagine things in the abstract and so this practical experience is imperative. If it is not feasible to run an actual UCC academic module, it is recommended that an accredited FETAC course, or equivalent, is built into the programme. This recommendation encourages the student to develop a practical solution based approach to structuring workload and organising deadlines whilst undergoing this pre college year. It is expected that this will assist them to acquire the skills which have been identified in a more meaningful way in comparison to learning them theoretically and not having the opportunity to apply them in a practical academic setting.

3) The research from the literature is unanimous in its suggestion that a specific, targeted programme for each student is necessary. The NLN programme can work with individual students to tailor a package of support and allow the student to self identify what supports they require. Once supports are acknowledged the programme can encourage students to identify their own strategies to manage difficult situations. This self identification of support needs could be used in a pre college programme as a means of preparation. Self identification can be empowering and enable the student to determine their own coping strategies to overcome difficulties which arise in the course of third level life.

4) A general education of what is expected of students in third level would be very useful. Many of the students expressed concern that they were just not sure of the expectations of them. As identified in the research, both in the literature and in the qualitative accounts, the sociological theory of the Hidden Curriculum can be challenging to students with AS. Even the simple

premise of knowing you can ask for help can be complex for a student with AS. Myles and Simpson (2001) argue that students with AS are at a disadvantage because they do not understand the Hidden Curriculum. As a result they inadvertently break the rules associated with it. Instruction and interpretation of hidden curriculum items such as learning social rules and norms and explicit instruction on expectations should be an integral part of a pre college programme.

5) Help with managing day to day living is an important part of success in third level for a student with AS. Tasks such as budgeting, shopping, cooking and self care should be discussed in this pre college year in order to prepare the student for successful independent living. If the student was proficient in these areas it may help in organising their overall time and increase their general quality of life whilst in college. This holistic approach would assist the students to succeed academically but also give them lifelong skills which would benefit every aspect of their lives into the future.

6) It is recommended that the NLN utilise other agencies to develop partnerships to provide a comprehensive support programme. Having strategic links with the Disability Support Service (DSS) in UCC is of crucial importance for the NLN. Throughout the research, the students acknowledged the support they received from the DSS. The pre college year should be used to develop an individual support plan which could be used as a guide for the DSS to continue to support the student throughout their college years. Another internal link with UCC which this research recommends is with the Occupational Therapy department. The Trinity College Dublin disability support service and its Unilink service with the OT department has been acknowledged by ASPIRE, the Irish Asperger's Syndrome Association in their consultation to the National Strategy for Higher Education (ASPIRE, 2009) as very useful in supporting students with AS. However they indicate that this support should be provided and made available by all third level institutions in Ireland. This is an opportunity for the proposed NLN programme to follow in its achievement. Involvement from an OT can assist in developing strategies with the student to overcome practical issues and difficulties associated with their condition.

The research also highlights that the issue of anxiety and depression is prevalent among the students with AS. Developing links with agencies specialist in prevention and treatment of these conditions can assist the students as the NLN programme co-ordinator can refer and advise the student as necessary.

These strategic links can offer a more comprehensive package of support for the student with AS throughout this programme.

7) Emanating from the literature is the need to educate service providers Madriaga et al (2006) concluded that many of the barriers faced by students with AS were not a result of their condition but they were perpetrated by poor practise and lack of disability awareness in the institutions. The NLN could examine the potential to offer consultancy to the institutions in UCC and other third level institutions to facilitate best practise in supporting students with AS.

8) The researcher also recommends that there is post college support for students with AS because although it was not explicitly relevant to this study, a number of students did express concern that once college is over they have to face new challenges in the workforce. Further research similar to this study is recommended in this area so the strategy for a post college programme is also driven by the opinions of the students with AS. A post college programme may involve advice on completing further study, guidance and assistance in applying for employment and skills and strategies for succeeding in the labour force. Knowing there is prospect of employment after education may act as a motivator to students with AS throughout their time in college.

Introduction

Background to the Research

The UCC Science Shop provides participatory research to a community organisation by allocating students to undertake a research project based on a specific topic acknowledged by the organisation. In this instance the participatory action research method was implemented in response to a research requirement by the NLN to identify the support needs of students with AS in third level education. The student and the community organisation worked collaboratively to determine the research hypothesis, the sample, the research methods and subsequently with the analysis and interpretation of the data. In partnership, the researcher and the NLN regional manager determined the research hypothesis and decided upon a research agenda. The ultimate goal of the research is to determine the needs of students with AS in third level based on the experience of the students themselves. In essence, the practical concerns that the students identify will be utilised to compile recommendations to the NLN with the objective of developing an effective pre college programme for students with AS.

Rationale and Significance of the Research

The NLN propose developing a pre college support programme for students with AS to prepare them through practical applied experiential learning. The researcher aims to provide a piece of work to the NLN which will provide an element of the foundation for the development of this programme. On completion of this project, it is envisioned that the results will be an accurate reflection of the student experience and provide a better understanding of what supports are needed for students with AS in order for them to successfully complete third level education. It is anticipated that qualitative interviews, in conjunction with a comprehensive literature review, will act as a guide for the development of a programme to enhance the supports for students with AS transitioning to third level education. The research seeks to discover the supports which the students recognise as being valuable to them and give them the opportunity to identify further supports which may improve their college experience and other students with AS in the future. The NLN has identified this research as imperative to ensure their proposed programme is meeting the needs of the students themselves and thus is in fitting with their person centred ethos. This person centred approach to service provision is at the heart of everything the organisation does and this is reflected in Individual Action Plans where each learner is central to the process and to the services provided.

A critical element of this participatory research is that the opinions of students with AS will be acknowledged. This is an empowering process for the students involved as it will assist in the development of a programme and engender positive change

Aims of the Research

The main aim of this research, guided by the requirement of the NLN, is to identify the support needs of students with AS in third level education. The goal of the organisation is to develop a pre college programme which has content appropriate to the needs of the students with AS. The researcher intends to compile recommendations to the NLN directed by the literature and the qualitative research and provide them with a comprehensive account of the identified needs of students with AS.

In order to achieve this aim the researcher sets out to:

- Complete a comprehensive literature review which will include legislative context for students with a disability, evidence to support the proposed NLN Programme, national and international examples of supports for students with AS in third level, research on transition to third level and best practise guidelines on participation of students with AS in education.
- Carry out a qualitative study of students with AS in UCC to gain a pragmatic insight into the lived experiences of their education and allow them to identify supports which they consider as essential

Research Questions

In conducting this participatory piece of research, refining the research questions was of fundamental importance to the researcher in order to interpret exactly what the NLN wanted to discover. In discussion with the NLN regional manager, the research questions were identified as follows:

1) Would students with AS use a pre college programme if it were developed?

2) Does the literature identify particular models of support for students with AS in third level education, and if so, what features of these models prove significant in delivering best practise support?

3) What do students with AS identify as the main areas in which they need support?

4) If a pre college programme were to be developed, what do the students with AS consider as vital to be included?

Conclusion

This piece of research is a collaborative approach between the NLN and a UCC student on behalf of the UCC Science shop. The above discussion highlights the importance of the participatory process in determining the focus of the study and the exact requirements of the organisation. It is anticipated that the research conclusions will be of critical importance to the development of the NLN programme. According to (MacCauley and Ryan, 2003) participatory research is a mutually rewarding educational experience for researchers and community members and enables tangible action based on research results. The outcomes based on the above aims and research questions are expected to promote the development of the NLN programme and thus the collaborative partnership in this research should improve the quality of service to students with AS in third level into the future.

Methodology

Introduction

This chapter will outline the methodology and theoretical framework which will be used to conduct the research. A qualitative and participatory method of research was employed to conduct the research underpinned with an interpretive approach.

Ethical Considerations

'Social research is conducted by, for, and about people, so there is always the potential to harm others' (Estenberg, 2002), therefore it is necessary to consider ethical issues when carrying out a social research study.

It is of fundamental importance to the researcher and the NLN that the research is ethical in its rationale, processes of data collection, treatment of the data and distribution of the findings. In order to comply with the basic principles of research ethics the research will be underpinned by the following reference:

"*...research ethics is about being clear about the nature of the agreement you have entered with your research subject. Ethical research involves getting the informed consent of those you are going to interview. It involves reaching an agreement about the use of this data and how its analysis will be reported and disseminated...It is all about keeping to such agreements which you have reached. Finally it is about representing the person's views fairly and consistently with their intended meanings."* (Blaxter, 1996)

This is reflective of the practice which will be utilised throughout this research. Due to the nature of the research being undertaken, the researcher contacted the UCC ethics committee in order to ascertain best practise guidelines in relation to interviewing a group of students with a disability. They advised that the research proposal should be submitted to the UCC ethics committee for approval to ensure that acceptable ethical guidelines are being upheld. The researcher submitted a proposal of the research to the ethics committee and received approval as they were satisfied there was no substantial ethical issues.

It is of extreme importance to the researcher that all participants were respected and treated with dignity throughout the process. All contribution was voluntary and the students who participated were made fully aware of the research aims from the outset.

The students signed an informed consent form before beginning the research process and therefore it is expected that they are fully aware of the procedures involved. It was made

explicitly clear that all participants had the right to withdraw from the research at any time without repercussion.

Based on the premise of honesty and integrity in research, the participants were informed of the proposed dissemination of the research findings. The researcher can certify anonymity and confidentiality to all the research subjects in respect of not revealing their names. However due to the small number in the target group and collaboration with the Disability Support Service in UCC, there may be some identifiable features in their interview responses. The respondents are aware that the research findings may be published by the NLN or the UCC Science Shop. Respondents were given the opportunity, if desired, to read the findings before publication and retract or amend quotes or opinions.

All interviews were recorded on a Dictaphone with prior consent from interviewees. The recordings of the interviews do not have any reference to the names of the students involved and will be held in a secure place until six months after the research is completed (to facilitate verification if required) They researcher will then safely destroy all recordings and transcripts.

Research Approach

The researcher is sensitive to the issues which may arise for students with AS in an interview setting. A literature review on best practice approaches to interviewing a student with AS was compiled by the researcher and the UCC Disability Support Service was consulted to ensure the questions and setting were appropriate to the needs of the respondents. Due to the variance of characteristics experienced by people with AS each interview was conducted based on the preference of the interviewee. On a case by case basis this involved the researcher varying locations and in one case splitting questions into two different interviews as the time frame was too long for the participant.

Qualitative Research

There are many options available to conduct research each with their own distinct advantages. The researcher examined a variety of literature on different research methods in order to decipher which technique was best suited to this particular research.

Qualitative research examines the construction of the social world by participants (Bryman, 2008). This type of research is open and allows the interviewer to understand the position of the participant in a meaningful way (Ritchie and Lewis, 2003).

"One of the best ways to understand a system or a process is through listening to the experience of the individual involved." (Seidman, 1991)

These quotes facilitated the decision to carry out qualitative interviews to achieve the results required to most suitably answer the research question. Qualitative interviewing provides a means of exploring the points of view of the students in UCC with AS and getting an insightful set of responses from them. This approach was discussed with the NLN and it was decided that a semi structured quantitative interview was the best approach for this research. A semi structured interview approach allowed the researcher to expand on and investigate relevant issues as they arose.

"*A major advantage of the interview is its adaptability. A skilful interviewer can follow up on ideas, probe responses and investigate motives and feelings which questionnaires can never do. Questionnaire responses have to be taken at face value, but a response in an interview can be developed and clarified*." (Bell, 1999)

Judith Bell refers to a common critique of using interviews as a research method. The criticism is that findings are not generalisable because there are too few subjects. A paradoxical answer from the history of social psychology is that if the aim of the study is to obtain general knowledge, then the most suitable way to conduct the research is to focus on a few intensive cases. (Bell, 1999)

A qualitative approach, according to Ritchie and Lewis (2003), provides in-depth and interpreted understanding of research participants by learning about their social circumstances, their experiences, perceptions and histories.

This approach meets the needs of the NLN as it will provide an understanding of the realistic, lived circumstances of the students with AS in their experiences of third level education.

Participatory Research

The theoretical approach of participatory research acts as a guide to the research methods utilized to complete the research.

"Small scale qualitative and rapid appraisal procedures aim to generate knowledge and information which represent the perceptions, concepts and practices of different groups and communities in a relatively short time. The emphasis is on generating knowledge from the perspective not only of the researchers but also of the researched. Qualitative research and rapid appraisals help to identify local needs and priorities, place issues in context of people's lives and give direction to programme development and service provision" (De Koning and Martin, 1996)

This excerpt emphasises that participatory research methods facilitate the generation of knowledge which the NLN require. The importance of interpreting the reality of the students being researched was of fundamental importance. The NLN emphasised the desire to build a programme around the needs and supports identified by the students who were researched.

The researcher worked closely with the NLN regional manager at all stages of the research. These stages include but were not limited to:

- Initiation
- Design
- Data Collection
- Data Analysis
- Interpretation of the Data
- Discussion, Presentation and Dissemination of the findings

A central principle outlined in 'The Commission on the Status of People with a Disability' (1996) is one of advocacy. It highlights the importance of facilitating people with a disability to have their views heard and acted upon.

It is envisioned that when the research is completed, the NLN, will use the findings as a way to empower the participants and future students with AS to complete their third level education. It will be an integrated approach between the researched, the researcher and the community organisation. This approach is in line with the theory of participatory research where *'participation should genuinely be empowering and not just a situation where groups work with a researcher for the latter's convenience.'* One of the unique qualities of participatory research is that of serving the shared interests of both researchers and researched. (De Koning and Martin, 1996)

In order to develop a targeted programme for students with AS it is crucial to listen to their specific solutions to problems and difficulties which they encountered. This will help to avoid mistakes and to develop a programme which will take into account the specific situation and conditions of the researched group and this will inevitably influence its outcome and success.

The students who participate in the interview process can be confident in the knowledge that they have contributed to the process of action to promote increased supports for students with AS into the future.

Theoretical Perspective

The research took an interpretative approach which provides representation and description of an experience. It is rich in detailed description and limited in abstraction. An interpretative analysis provides understanding and insight into the everyday experiences of the students with AS being researched. Weber introduced an interpretative approach to social science research through the concept of 'Verstehen.' This approach involves an empathic understanding of the phenomena experienced by the research participants. Interpretative approach is about finding participants interpretation and perspectives on situations at a particular time. In contrast to the scientific positivist approach to measuring the social world this view holds that how we understand and write about human knowledge must be through interpreting the social world by how individuals themselves experience it (Ritchie & Lewis, 2003).

Interpretivism attempts to understand the social world which has been created through lived experiences which continue to be reproduced through daily activities (Blaikie, 2003).

A phenomenological perspective is linked with interpretivism and can be simply described as '*the meaning for several individuals of their lived experiences of a concept or a phenomenon*' (Creswell, 2007: 57). A researcher applying phenomenology is concerned with the lived experiences of the people.

This interpretative phenomenological approach is viewed by the researcher as a means of achieving the desired result and understanding the experiences of students with AS. This approach is also aligned to the objectives of the NLN and the outcome they require from this process.

Designing the Research Instruments

The interview guide was drawn up by the researcher in collaboration with the NLN and the Disability Support Service in UCC. The rationale for a collaborative approach is to gain relevant data for the organisation whilst also working with the disability service to ensure suitability for the target group. The NLN require particular information from the students with AS in order to meet the objectives of this research. Consequently it was of utmost importance for the researcher to design the interview questions in participation with them.

The researcher also examined data on best practise in interviewing people with AS before attempting to draw up the questions. The researcher was mindful of the nature of the participant group and the potential problems they may face with social interaction and ensuing anxiety. The

interviewer gave all participants choice over where the interviews were conducted so the venue was a setting where the interviewee was comfortable.

As Bell (1999) alludes to, interviews can be adapted to suit the interviewee. This flexibility is imperative for the researcher in this study, as the students with AS may have varying levels of comprehension, communication and social skills. It was important to the researcher that flexibility was offered as this allowed the interviews to be based on the preferences of the interviewee in terms of timing, pace and location. Accordingly the interview process was flexible and informal so the target group were as relaxed as possible in what may be a stressful social experience for them based on the characteristics of their condition.

Choosing the Sample

The aims of this study dictated that all of the respondents needed to have a diagnosis of AS in order to participate. In order to get a representative sample, the researcher had to utilise a purposive sampling technique. Due to the scope of this project and in discussion with the NLN it was decided to focus this research on the main third level institutions in Cork, namely UCC. The researcher contacted the UCC Disability Support Service and explained the research. Due to the confidential nature of their support to students, there was initial reluctance from the support services to provide names of students with AS registered with them. However this problem was overcome by having a three way meeting with the disability support officer, the researcher and the NLN Regional Manager. Once the rationale was clearly explained and the Disability Support Service understood the validity of the research and the benefits of the proposed NLN programme, they agreed to email all the students with AS linked in with the service and introduce the research to them. There was emphasises from the Disability Support Service that it was of upmost importance that the research be conducted with integrity and avoiding any harm to the participants.

Polkinghorne (1989) suggests that research using a phenomenological perspective should involve at least five participants who have experienced the phenomenon (cited in Creswell, 2007). The initial expectation of the researcher and the NLN was that six students will be interviewed. However, the final number of students interviewed was eight.

In order to trace additional participants the researcher used snowball sampling. Snowballing is a method of expanding the sample by asking one informant or participant to recommend others for interviewing (Crabtree & Miller, 1992)

A student with a diagnosis of AS who completed a Masters in UCC is now employed as a peer mentor to other students with AS. This person made contact through the Disability Support Service offering to do an interview. This person subsequently, through working with AS students, explained the perceived benefits of this research to them and encouraged and facilitated interview participation of a further 4 students.

Boundaries and Limitations

The researcher in this project is employed by an organisation which frequently provides a service for people with AS and therefore has an understanding of the potential challenges faced by people with this diagnosis. Although the researcher aimed to remain objective throughout the process, May (2001) argues that it is '*difficult to create the right environment to gain qualitative data, while also being detached and objective'* (May, 2001 pg 127). By applying the framework of interpretivism and using semi-structured interviews, the researcher immediately imposed some methodological limitations on the study. An interpretivist perspective recognises that a researcher cannot be entirely objective and that his/her interpretation of what is said is inevitably influenced by their values and outlook on life (Snape and Spencer, 2003)

The researcher is aware that this inherent knowledge of AS and the methods chosen to complete the research may produce a subjective opinion. Total objectivity is difficult to achieve but acknowledging and being aware of the potential for bias helps in the objectivity.

Phenomenological studies make detailed comments about individual situations which do not lend themselves to direct generalisation in the same way which is sometimes claimed for survey research. Due to the scope of this study, it is recognised that the finding are only relevant to the students who have been interviewed and may only be pertinent to UCC. Although the themes and issues which emerge from this research will be valid and applicable to students with AS in other third level institutions, it will not provide an exhaustive list of supports required. However, the researcher believes that this will be overcome by a comprehensive review of the literature in the area of support in third level for students with AS worldwide. The data obtained from the interviews together with the best practise approaches as defined by the literature will provide a complete view of the supports needed.

The social skill deficits which are characteristic of many people with a diagnosis of AS may create a limitation on the volume of data which the students with AS discuss with the researcher. To overcome this, the researcher has endeavoured to create an interview environment based on the desire of the student being interviewed.

Conclusion

This chapter describes the methodology used in this research. Through the UCC Science Shop, the study was a participatory research project in conjunction with the NLN. The research involved secondary research in the form of a literature review and 8 semi structured interviews as primary qualitative research. Limitations have been recognised and ethical considerations have been emphasised. The findings and recommendations from this piece of research will form the basis for the development of a NLN programme to support students with AS in third level education.

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Literature Review

Introduction

Due to the participatory nature of this project the focus for the literature review was decided in collaboration with the NLN. In order for them to create a programme which is relevant and appropriate to the needs of the students they propose to assist, a review of the literature to act as a guide to inform best practise approaches was critical. The NLN expressed a desire for the literature review to look at other research in this area and also to look at initiatives which may be used in other third level institutions worldwide in relation to supporting students with AS. Although the qualitative research is of fundamental importance for the proposed NLN programme, there is invaluable information to be gathered from reviewing the literature in this area.

This chapter will review existing relevant literature in order to thematically assess supports the NLN could build into a pre college programme. In addition a critique of the literature will produce a rationale for the importance of this programme. A comprehensive review of existing information in this area will also identify gaps in the literature for further research.

The research has a specific purpose for the NLN. For this reason this literature review will not focus on the definitions and characterisation of AS. The NLN organisation, by the nature and focus of its work, has an intrinsic understanding of AS and therefore does not require an in-depth explanation. As a participatory project, the researcher wanted to make the literature review as relevant as possible for the organisation and thus comprehensive description of AS will not be included in this section. Additional information is included in Appendix One for other readers who may not be as familiar with the characteristics of AS

This literature review will be broken down into the following sections.

- Legislative Context for Students with a Disability
- Evidence to Support the Proposed NLN Network Programme
- Transition to University
- Supports Internationally for Students with Asperger's Syndrome
- Best Practise Interventions

Legislative Context for Students with a Disability

Although this research is specific to students with AS, in order to set context it is important to examine the general policy and legislation in regard to students with a disability. In doing so, it will validate the need for adequate supports to uphold the fundamental statutory rights of all students with a disability for inclusive education.

The benchmark for equality of opportunity for all people in terms of education comes originally from the Universal Declaration of Human Rights 1948. This declaration emphasized values and beliefs and provided an inherent entitlement of all humans to be treated equally and with dignity without distinction.

Article 13 of the International Covenant on Economic, Social and Cultural Rights 1966

"recognise the right of everyone to education...education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms."

In 1993 the UN Standard Rules of the Equalization of Opportunity for Persons with Disabilities was a set of rules to guide policy makers but was not a legally binding instrument. Rule 6 of this UN Standard concerns education and recommends that

"States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system." (UN Enable - Standard Rules, Overview. 2012)

Although it was not legally binding it indicated best practise for national Governments in relation to people with disabilities and was the foundation for the subsequent implementation of Acts into Irish legislation.

The Convention on the Rights of Persons with Disabilities 2007 has basic principles which could be utilised to emphasize the rights of inclusive education for people with a disability. These principles include respect for inherent dignity, non discrimination, participation and inclusion in society, accessibility and equality of opportunity. Furthermore Article 24 of this Convention deals exclusively with the issue of Education.

"States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system" (Convention on the Rights of Persons with Disabilities 2007)

The Charter of Fundamental Rights of the European Union 2000 sets out in a single text, for the first time in the European Union's history, the whole range of civil, political, economic and social

rights of European citizens and all persons resident in the EU. It prohibits discrimination on the grounds of disability (Article 21) and recognises the right of persons with a disability to independence, social and occupational integration and participation. Article 14 states that everyone has a right to education.

A protocol in 1998 to the European Convention on Human Rights stipulates that 'No person shall be denied the right to education.'

As a member of the European Union, Ireland is bound by the above international regulations and thus they will form the basis for Irish law.

In the last number of decades there has been unprecedented policy change to advance the rights of people with a disability in Ireland. There has been emphasis on inclusion and equality for people with disabilities in every aspect of social life, including education. A range of legislation has been passed in Ireland which has incorporated provision for people with disabilities over recent years. In Towards 2016, the current social partnerships agreement, there is a recommendation to increase provision of services for those with special educational needs (Section 13). Section 33 of the agreement is specifically focused on policy for people with a disability and the overall vision is that people with a disability have the opportunity to achieve their potential, live a full life without discrimination and have equality of access to all societal services. This includes particular emphasis on the right to education appropriate to the individual needs and ability. (Government of Ireland, 2006)

The Equal Status Acts 2000-2004 prohibits discrimination on nine grounds, one of which is disability. The Acts stipulates that educational institutions must do all that is reasonable to accommodate the needs of people with a disability. (Government of Ireland, 2000)

Three pieces of legislation in respect of education of people with a disability are especially pertinent to this study. These are the Education Act (1998), the Disability Act (2005) and the Education for Persons with Special Educational Needs (EPSEN) Act (2004).

The Education Act (1998) was the first comprehensive education statute which established a statutory basis for the provision of education in Ireland. The Act requires institutions to publish admission policies, including admission and participation of people with disabilities. This legislation supports the non discrimination of students with a disability.

Section 26 of the Disability Act 2005 requires all public bodies, including publicly-funded education providers, to ensure that access by people with disabilities to their services is a fully integrated element of overall service provision. The Disability Act envisages that providers start

to move beyond 'accommodating to avoid discriminating' to a position of more proactively ensuring access to services as part of mainstream service provision

The Disability Act provides for a process of health and education needs assessment by the HSE. The NCSE (National Council for Special Education) assist the HSE in the assessment of the needs of adults with a disability in education, including higher education. The Act also provides that the NCSE will consult with education providers. If the person continues in the education system (taking a place in higher education), under the terms of the Disability Act supports will be put in place to ensure reasonable accommodations are provided by the institution to ensure as far as possible that the person can participate equitably.

The EPSEN (Education for Persons with Special Needs) Act refers specifically to 'special educational needs' which are defined as

'a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition'.

Section 15 of The EPSEN Act specifies that provision should be made in an education plan "to assist the child to continue his or her education or training on becoming an adult." In doing so the Act states that education providers should

"take such steps as are necessary as will enable the child to progress as a young adult to the level of education or training that meets his or her wishes or those of his or her parents and that are appropriate to his or her ability"

The above discussion of the legal framework and policy initiatives in an Irish context in relation to education of students with a disability demonstrates that the NLN programme which is proposed has legitimacy in the legal framework and is an identified need as supported by national policy documents. Students with AS have a right to an inclusive education and provision of a specific support programme to enable them to succeed.

Evidence to Support the Proposed NLN Network Programme

An OECD report compiled by the National Office for Equity of Access to Higher Education in 2010 illustrated the increase in participation of students with a disability in mainstream education. Between 2005 and 2008 there was a 46% increase in provision of reasonable accommodation in State Examinations for students with a disability. The report concluded that although this demonstrates the increase in opportunity for students with a disability in mainstream education it also highlights the continuing need for a variety of services for students

with a disability into the future. This increase in students with a disability in state examinations invariably will contribute to a need for support in the next level of education.

A survey by Association for Higher Education Access and Disability (AHEAD) in 2010/2011 found 23 higher education institutions in Ireland identified a total of 6,932 students with disabilities, representing 3.9% of the total student population, of which 6328 are studying undergraduate courses and 604 are studying postgraduate courses. This represents a 10% rise in the number of students with disabilities from 09/10, when the figure was 6,321 and a rise in the percentage of the total student population they represent from 3.3% in 09/10 to 3.9%.

Of these students with a disability, 160 are registered as having Asperger's Syndrome. (AHEAD, 2011)

The National Plan for Equity of Access to Higher Education 2008-2013 set a target to double the figure of students with a sensory, physical and multiple disabilities in higher education by 2013 through greater opportunities and support. Many AS students could be categorised as having a sensory disability. As part of this proposed increase the report suggests a model of support for effective access programmes. The suggestions include a focused programme designed to achieve the targets set. It should include:

"pre-entry activities for students from all under-represented groups with special emphasis on working with teachers in targeted primary and junior cycle second level schools and with community-based partnership groups;
Individual and group support for new entrants in their first year, including personal, social, financial and academic assistance where necessary.
A full agenda for action agreed between the institution and its partners in local communities, aimed at promoting clear routes of progression to higher education for targeted groups of learners.
A commitment to engage students and their families, specialised expert bodies, community agencies and representative groups in planning and monitoring access programme activities.
(National Office of Equity of Access to Higher Education, 2008 pg 85)

This specification is in line with the proposed programme the NLN aspire to develop. The suggestion in this report that pre entry activities by a community based group in participation with schools, the institution, the student and the family to include personal, social, financial and academic assistance would be beneficial establishes the need for the proposed NLN programme. Devising the programme effectively in collaboration with the student, the family and the institution creates the potential to increase participation and achieve the target as suggested by the National Office of Equity of Access to Higher Education.

Pre entry access programmes by third level institutions traditionally have focused on increasing participation of students from socio economic disadvantaged communities. There is an apparent

gap in the transition plan for those with a disability. Disability Access Route to Education (DARE)[1] is a university admissions scheme for students with a disability. It offers places in University on a reduced CAO points basis to students with a disability. However all students with AS may not need this provision. Students with AS have very different needs than other students with a disability and thus a specific programme would be more beneficial. Students with AS may have average or above average intelligence but they have major difficulty based on their social deficit and poor levels of understanding.

The authorities who decide on entitlement to disability services are sometimes unaware of the extent and significance of the disabilities involved in AS. Proficient verbal expression skills, overall IQ within the normal or above normal range, and a solitary lifestyle often mask outstanding deficiencies observed primarily in novel or otherwise socially demanding situations, thus decreasing other people's perception of their very salient needs for supportive intervention (Klin et al, 2000. p. 342).

The need for a specific programme, designed explicitly for students with AS, is undisputed as a best practise approach to support students with AS in third level education.

A conference by the National Federation of Voluntary Bodies on inclusive education held in Dublin in 2009 included a presentation by Julie O'Leary, a student with a disability who graduated with a Masters degree. Her main message in relation to supporting students with a disability was that 'services need to listen to the person; only then will they find the right solution.'

Another speaker at this conference was Franz Wolfmayer the president of EASPD (European Association of Service Providers for Persons with a Disability). He also emphasised the need for a support service which 'listens to those they support and adapt accordingly' [2]

Both of these statements highlight the need for a service which is developed in agreement with what the student identify as their own requirements. Supporting a student with AS can be made more complex by the clinical characteristics of the condition. The student may have poor communication skills to enable them to ask for assistance or they may have a lack of a desire to interact with support services. A pre college programme can develop the communication skills and increase confidence. The proposed NLN pre college programme upholds this form of support. They want to develop a programme which is based on the requirements recognised and identified by the students and is specific to their particular needs.

[1] http://www.accesscollege.ie/dare/index.php
[2] Conference details available from http://fedvol.ie/_fileupload/Education/Report%20Conference%20for%20website.pdf

Transition to University

The legal framework around education of people with a disability has enhanced in recent years and thus stimulated growth in support services. In relation to students with AS, there has been an increase in Autism and AS specific units developed in many mainstream primary schools. This support is welcomed but can leave the transition to third level education more difficult as a dependency may have been maintained through primary and second level education. The setting in a primary or secondary school is a more controlled environment with structured classes all day, more familiarity, smaller spaces and a relatively unvarying schedule. The transition from a structured, predicable environment in secondary school to the freer environment of higher education is likely to present particular challenges to students with AS (MacLeod & Green, 2009) Transitioning to university life can be a very difficult time for any student. The transition to university for a person with AS is particularly challenging due to unique characteristics of their condition. Unlike conditions involving the visible challenges of impaired mobility, coordination and vision, AS is relatively invisible. As a result, the potential for success can be overestimated for these individuals, leading to a lack of preparation and support for a realistic transition to adulthood.

Geller and Greenberg (2010) state that transition planning is often the weakest link in a student's education plan.

"*Through the transition plan, school personnel, families, and community providers should be helping the individual on the spectrum develop the wide array of skills identified in that learner's unique transition program"*

Aquamarine Blue 5 is a collection of personal stories of lived experiences in university of students with AS. Garry expresses that the stress and effort of trying to initially fit in produced exhaustion and anxiety and led to lower self esteem, falling grades and depression. (Prince-Hughes, 2002, pg 1) Another student says that 'sometimes reaching out and communicating isn't easy' (pg 179)

The Hidden Curriculum is a sociological concept which argues that basic norms and expectations are understood by students without having to be explicitly taught to them. Socialisation processes and knowledge of social norms and values often occur naturally through absorption in the education system. However this unspoken curriculum is difficult for students with AS. An article by Myles and Simpson (2001) argues that students with AS are at a disadvantage because they do not understand the hidden curriculum. As a result they inadvertently break the rules associated

with it. Instruction and interpretation of hidden curriculum items should be an integral part of the education of youths with AS. Adolescents with Aspergers will not learn social rules by merely placing them in social situations or through observation (Graetz & Spampinato, 2008). Consequently, any programme for students with AS will need to include explicit instruction on social values and norms.

A study completed in Trinity College Dublin (Gleeson et al 2010) concluded that:

"Given the nature of the third level social, institutional and physical environment and the typical characteristics / impairments of individuals with AS, many are likely to face certain challenges when coming to college. Tailor-made support services that understand the particular and individual difficulties of students with AS are required to facilitate students' participation in all aspects of college life, and enable students realise their abilities so that they can develop both personally and academically."

The study explains that the infrequent contact hours and non-obligatory attendance can impact adversely on the ability of students with AS to connect with the college community, make friends and establish a peer network. Additionally, the study states that many students with AS experience difficulty with executive functioning skills. This impacts on their ability to organise and manage their time (and thus meet assignment deadlines), prioritise activities, structure and plan assignments, and set goals. Students may also find it difficult to negotiate the systems within college such as the library and administrative policies. (Gleeson et al 2010)

This study provides a comprehensive foundation, in an Irish context, of the transition process of students with AS into third level and the supports which should be provided to assist in the move into third level.

Madriaga et al (2006) concluded that many of the barriers faced by students with AS were not a result of their condition. They were perpetrated by poor practise and lack of disability awareness in the institutions. The NLN could examine the potential to offer consultancy to the institutions in UCC to facilitate best practise in supporting students with AS.

A recommendation from the authors also underpinned the need for an individualised assessment of need and a support programme which included student input.

"A needs assessment for students with AS is strongly encouraged due to the multifaceted aspects of the condition. This diversity requires diverse support needs. Supporting students with AS requires creative thinking as well as the students input on what he or she may require" (Madriaga et al 2006)

The study also made a recommendation for more focused research into specific impairments and higher education transitions to better inform policy and practise.

An individual needs assessment is also supported by Smith (2007). This study aimed to discover in what ways institutions can better serve students with AS. The research finds that difficulties which students with AS encounter are diverse. This study established that students with AS are provided with supports that were created for students with other disabilities. Consequently these will not always satisfy the needs of students with AS. They recommended an individual assessment of need be completed on each student to identify individual needs. (Smith 2007)
A pre college support programme like the NLN are suggesting could facilitate an assessment process which would then be used as a guide for the institution to develop supports for the student with AS throughout their college experience.

Blamires and Gee (2000) stated that students with AS may benefit from longer induction periods with specific support in relation to orientation. Similar to other research in the area Blamires and Gee also emphasised the need for flexibility in the approach of supports for students with AS.

'Flexibility in lectures, exams arrangements, orientation training, placements and training of key members of staff can be an essential prerequisite for students successfully completing their academic careers. This does not have to compromise academic requirements.' (Blamires & Gee, 2002)

Awareness and understanding of peers may lead to more successful interactions both in relation to tasks and to social activities. If a student decides to disclose his/her needs to peers, s/he may need support to do so. Peer support may promote collaborative interaction, co-operation and negotiation. (Howley, 2005)
Peer support and understanding is a sensitive issue. Students with AS may have different views about disclosing their disability to their lecturers or peers. However it is fundamentally important that the individual student's right to confidentially is respected and no disclosure should be made without prior consent.

A longitudinal study completed in the U.K. by Madriaga and Goodley (2010) gained valuable insight into transitioning to further education for students with AS. The authors in this study also addressed the challenge that institutions face in facilitating people with AS.

'Although well intentioned, suggestions such as not assigning group work or constructing separate catering outlets for students with AS may actually perpetrate marginalisation' (Madriaga and Goodley, 2010)

The study suggests that supports need to be diverse to meet the individualised needs of students. Inclusive education, the research contends, needs to engage more directly with specific issues faced by learners with AS.

The value in the programme suggested by the NLN is that the supports will come from suggestions the students make themselves and thus it is an inclusive process and not actively marginalising students.

The university environment is actually a space where a person with AS could prosper with the correct support. In a book by (Harpur et al 2002) *Succeeding in College with Asperger's Syndrome: A Student Guide* there is an assumption made that third level education can be an area where a student with AS could thrive.

"Not only will college allow you to pursue your area of interest, but it will also reward you like never before for being successful in that area. It is fair to comment that of all environments in which people study, train and work, college is probably the one place where the strengths of AS, such as the single-minded pursuit of a subject, are really recognised and valued" (p. 33-34)

This suggestion that life in third level can benefit a student with AS and is a positive stage in their educational development is indicated in other research.

A report by Madriaga et al (2006) established that students with AS had a euphoria about starting third level education as it was a way of them starting a new life.

"Attending university gave them a chance to place negative experiences of school, such as social isolation and bullying, behind them. With the prospects of meeting new people, respondents embraced the opportunity for reinvention"

The suggestion that college can be a positive environment for a student with AS is an issue which could be used to the advantage of a support programme. By focusing on the positive aspects of college experience, it could empower the student to realise their potential. A pre college programme should develop on the characteristics of AS which can be utilised in a constructive way in a third level environment.

Supports Internationally for Students with Asperger's Syndrome

Most universities have some form of disability support service in operation to provide assistance to students with a wide range of special needs. In initial discussion with the NLN, they expressed the desire to research what other transition programmes were operating worldwide for students with AS.

This section will look briefly at a number of support programmes for students with AS. Not surprisingly, the majority of innovative, best practise programmes are located in the USA.

The University of Connecticut[3] has developed a first year experience course specifically for students with AS. The course includes essential information about social skills, how to adapt to new schedules and environments and provides an opportunity for students to meet with their peers. This programme is run for one year and whilst completing it the students take one academic module which adds to the credits of their degree. Although the student is on campus and takes one module, the course is effectively a pre college programme as it is run for one year prior to entry to the full degree.

The combination of doing an academic module alongside the pre college programme is an innovative way of supporting the students through genuine academic situations.

The following programmes are support programmes run in conjunction with the student entering their first year of college and thus not a pre college programme. However, examining the content highlights best practise approaches to supporting students with AS in third level.

The West Virginia Autism Training Centre at Marshall University[4] set up a College Support Programme for Students with AS in 2002. The program exists to offer appropriate academic, social and independent living skill supports to individuals with AS so that they may have a successful college experience and learn skills necessary to enter a competitive workforce. A positive behaviour support approach is used to assess each student's needs and develop appropriate academic, social and life skills supports. Students meet regularly with the programme staff and their positive behaviour support teams to monitor progress, develop to-do lists and identify new goals. Each student, along with his or her family, participates in person-centred planning prior to the first semester which determines action plans for the year ahead. Faculty, staff, and tutors receive training related to AS, and specific information about the unique characteristics and learning style of the participating student. The programme includes supports in learning strategies for organisational skills, supported periodic meetings with their professors.

The researcher concludes that this package is a comprehensive support system to student with AS and by combining it with an academic module it allows for experiential, practical learning.

[3] http://www.csd.uconn.edu/sead_program.html
[4] http://www.marshall.edu/atc/

The University of Alabama (UA-ACTS) have a specific programme for students with AS which includes provides individualized services to help students develop appropriate skills for self-advocacy, academics, daily living, and social interactions that will contribute to their success as independent adults. UA-ACTS provides support for the transition into a traditional university campus and toward achieving goals for the future.[5]

The Kelly Autism Programme at Western Kentucky University provides a residential mentoring programme which includes work on functioning skills (organization, prioritizing work, etc) as well as tutoring and peer mentoring.[6]

In the USA there are also a number of private national organisations which provide support programmes for students with AS in higher education. AHEADD[7] (Achieving in Higher Education with Autism/Developmental Disabilities) is a private, community organisation that provides support for students in higher education.

CIP (College Internship Programme) is a year-round residential program which focuses on social, executive functioning, academic, career and life skills while students are enrolled in a college course.[8]

CLE (College Living Experience) Each student receives academic, independent living and social skills instruction for a period of 12 months from a team of professionals whose goal is to help him or her become more self-sufficient, independent and confident.[9]

However many of these programmes and residential support programmes described above incur a substantial cost. A cost for service provision would be prohibitive and thus discriminatory to the student. The conflict here is that if these are considered reasonable accommodations for the students, then the students cannot be charged (Grossman, 2001).

In an Irish context Trinity College Dublin has a comprehensive support service for students with AS.[10] Unilink is a service which is run by the Department of Occupational Therapy and the Disability Service as a practical way to support students with AS. Since 2006 a designated

[5] http://bama.ua.edu/~uaacts/UA-ACTS/UAACTSbrochure2010.pdf
[6] http://kap.wku.edu/
[7] http://aheadd.org/index.html
[8] http://www.collegeinternshipprogram.com/index.html
[9] http://www.experiencecle.com/home.aspx
[10] http://www.tcd.ie/disability/AS/index.html

occupational therapist was employed to work specifically with students with AS in order to support their unique needs and to develop a specialist AS strand within the Unilink Service that caters specifically for these students.

The Unilink service produced a guide[11] which recommends an array of academic and social supports to assist students with AS to successfully complete their education. Academic supports include strategies to prepare for lectures, using the library, essay writing, study skills and exam preparation. Social supports recommended include socially appropriate/inappropriate behaviours and interaction with peers.

ASPIRE, the Irish Asperger's Syndrome Association highlight in their consultation to the National Strategy for Higher Education (ASPIRE, 2009) that the Unilink Service is very useful in supporting students with Asperger's Syndrome, however they indicate that this support should be provided and made available by all third level institutions in Ireland.

Best Practise Interventions

Although the NLN proposed programme highlights the importance of the student themselves informing improvements in practise, it is also imperative to look at research and expertise into useful strategies which are likely to be effective in supporting students with AS. A study by Sheffield Hallam University in the UK (Martin, 2008) concluded that:

"Achievement is most likely if systems can be in place from before the start of the course, and organised in such a way that parameters are communicated explicitly and sufficient flexibility is planned"

One of the main recommendations of the study is that:

"Before entry to higher education, is some sort of transitional planning possible so that the student has time to familiarise him or herself with the environment they are moving into. It is desirable for the learner to try things out because of their potentially having difficulty with imagining new situations in the abstract" (Martin, 2008 pg 89)

This study also highlighted the most important strategies for students with AS to succeed in college. These include developing a clear timetable from the start and enabling the student to understand that any changes will be notified in advance so anxiety and stress is reduced when change occurs. Another finding is that college needs to be seen as a holistic environment and not merely academic.

[11] Written by Kenny, Z and Treanor, D and available from http://www.tcd.ie/disability/AS/index.html

"Planning to enable the learner with AS to manage practically and socially may be required.... The potential for social isolation and possible lack of independent living skills, such as cooking and managing money, are important considerations and support with these aspects of life can mean the difference between success and failure" (Martin, 2008 pg 90)

Beardon and Edmonds (2007) highlight the importance of students with AS getting support with study skills, supported by the following quote from a student with AS who was interviewed as part of the research:

"I had some study skills tuition, as I had difficulty being able to grasp the necessary study skills, and extra time for exams, as I had much difficulty working under pressure. After I had this support, my work became comparable with others and I got better marks than other students who said that I wasn't good enough" (Beardon and Edmonds, 2007)

Attwood suggests developing strategies to encourage greater competence in the skills necessary to achieve improve social integration especially with peers. Social Stories are one such strategy written with the intention of providing information and guidance for what people in a given situation are doing , thinking, or feeling, the sequence of events, and identifying the who, what, where, and when of social situations (Attwood, 2000)

A qualitative study of students with AS concluded that social integration, self regulation, and organizational skills have an impact on the individuals' self-esteem and motivation to continue into postsecondary educational programs. Therefore these strategies are essential to be included in a support programme. This study also contends that that independence and self-advocacy skills should be embedded within student educational goals (Pepper, 2010)

Although academic supports are essential, there needs to be a holistic support package to ensure success for students with AS. A variety of supports may provide some assistance for students academically; however, the supports for life skills such as social and emotional well-being, coping with feelings of fear, anxiety, and stress may not often be addressed (Graetz & Spampinato, 2008).

Individuals with AS need to consciously learn the skills most of us acquire intuitively. Students with AS need to be supported to learn these skills. Therefore there needs to be practical help and social skills development built into the pre college programme. Social skills must be learnt in the context of social situations. Teaching skills in a natural setting can lead to improvements in social skills. (Meyer, 2001)

There has been some success reported in the literature for teaching and applying social skills in a support group format where opportunities are provided for interacting and practising new skills. Ozonoff and Miller (1995) conducted a study which involved a group work of adolescents with

AS. The aim was to teach specific interactional and conversational skills and provide explicit and systematic instruction in the underlying social-cognitive principles necessary to infer the mental state of others. The findings concluded that systematic instruction was able to substantially improve social and cognitive performance of the adolescents with AS. Myles (2002) and Mesibov (1984) suggested that teaching social skills in a group setting allows participants to develop new skills while using these skills to form relationships within the context of the group.

In an Irish context the support service mentioned above in Trinity College includes the development of academic, time management and organisational skills; anxiety and illness management, life style design and progress in the area of social relationships. Intervention strategies are typically practical, for example, preparing timetables with students so that they know what to do, where and when; role-playing social situations; and using writing techniques to overcome procrastination, and are employed according to need. (Gleeson et al 2010)

The Trinity College service has a website which includes YouTube videos of students with AS speaking about their college experience. One of the students (Finn) mentioned that

"AS can make standard difficulties worse. Balance between academic work and social life can be difficult for those with AS as they have a tendency to hyper focus on a particular task to the exclusion of everything else and be able to recognise when that balance is unhealthy"[12]

A support service should focus on enabling students to get this balance right.

Enabling is a key word when providing support services. If too much assistance is provided students will depend on the support provided rather than develop the skills necessary to make their own decisions and become self determined. (Wenzel and Rowley, 2010) Students do need to show responsibility and develop lifelong coping mechanisms.

Adams and Holland (2006) have encouraged higher education providers to undertake research to provide a sound evidence base to inform future interventions. This should focus on the impact of existing activities but also include greater opportunities for the student voice to be heard. This research is facilitating the students with AS to have their voice heard to inform a future intervention. The programme which the NLN suggest will influenced by the needs identified by the students.

[12] http://www.tcd.ie/disability/AS/index.html#!prettyPhoto/3/

Conclusion

A review of the literature has examined the legislative background to inclusive education. This foundation highlights the entitlement of all students with a disability, in this case AS, to an education with supports to meet their full potential.

Existing research supports the importance for students with AS to have interventions and strategies based on individual needs. There is evidence in the literature that a pre college programme would meet these needs. The literature also suggests that

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Findings and Analysis

Introduction

This chapter presents the findings from the primary research carried out through eight semi structured interviews. Themes that emerged throughout the analysis will then be explored in light of the existing literature outlined in Chapter Two.

As phenomenology encourages, reference will not be made to individuals but the information will be presented from the perspective of the group as a whole. The narrative accounts presented themes which will be supported by verbatim extracts from participants. A phenomenological perspective involves the researcher interpreting the data and interpreting the experiences of the collective group (Creswell, 2007).

To facilitate interpretation of the data the transcripts of the interviews were analysed using Interpretative Phenomenological Analysis (IPA). IPA has its roots in psychology, and recognises 'the central role for the analyst' in making sense of the personal experiences of research participants (Smith 2004). Both by coding and analysing data the researcher uses their personal knowledge and experiences as tools to make sense of the material (McCracken, 1988).

The transcripts were read numerous times to gain insight and interpret the information provided by the interviewees. This analysis involved the classification of emerging patterns, general themes and crucial points which were then used to refine the findings.

The importance of the inherent meanings in the interviewees experience will be discussed in relation to the NLN's proposed programme. Implications for the NLN initiating a pre college programme will be highlighted throughout this discussion.

Would students use a pre college programme?

In order to set a context for the research, the interviewees were given an explanation of the pre college programme which the NLN were proposing. It was crucial for the NLN to determine if there was a significant interest from students with AS in completing a pre college programme to verify the need for its introduction.

Of the eight interviews, four commented that they would have valued a pre college programme if it were in place at the time they began in UCC.

However, there was concern identified about the extra cost of accommodation and general living by adding another year on top of a degree programme. The consensus was that there would need

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to be parental support for the programme, as generally the main burden of extra cost would fall on the parents. Parental support was vitally important for the majority of the students. The researcher deduces that the views of parents may influence the take up rate of the programme.

However outside of this concern about extra cost there was interest in the idea of the programme. One of the participants was a student in UCC who had previously been enrolled in another third level institution. He had failed first year in his previous setting. He commented that:

"If I had the preparations put in place I might have succeeded first time. I liked the course and met good people but I just was not prepared for the change that college would bring."

He went on to add that

"it made my anxiety worse as I had to begin all over again in a new college, meet new people and find my way around and I was worried about failing again. I was naive and unprepared. If I had a year first to prepare like this programme then maybe I wouldn't have failed"

In hindsight, for this student, a pre college year would have been an effective way to make the preparations which he identifies as deficient and reason for failing.

Another student saw the problem with a pre college year being:

"I think when you finish the Leaving Cert there is a big rush to make use of it immediately and push into third level. Deferring for a year for a pre college programme would not be on the agenda of most people, especially when you have the pressures socially, from family and friends. I think I wouldn't like having to explain to people what the year is about. Most students with AS feel that getting their place in college is proof enough that they are capable of being there."

However following this response, the same student went on to state that on reflection he felt that it would be beneficial in the long run because it might make college easier if you were more prepared.

"I don't think I would have done it but now that I am in second year and am struggling I can see how being prepared would be good. It might make things easier"

Another student, now in third year, who had to repeat exams in both first and second year said that

"From my own experience I would have really benefitted from that kind of support prior to starting. I ended up failing lots of my modules and having to repeat in the summer due to unorganisation but when you are going into college and getting excited about that new start, it is hard to see it from that perspective."

The respondents were, in general, positive to the idea of a pre college programme. Even those who said that they would not do it could see the advantage of it. The researcher concludes from the responses that it is only with retrospective observation that the full benefits of this proposed

programme become apparent to the students with AS. Consequently, it could be very useful to run open evenings on the programme for parents and prospective students which include input from AS students who have experienced the difficulties which college life brings. By hearing evidence of the lived experiences of students with AS it can highlight the necessity for support and put emphasis on the advantages of a pre college support programme.

Experiences of Students with Asperger's Syndrome

The following sections highlight the lived experiences of the students with AS who were interviewed. The NLN explicitly wanted the contribution of students with AS in order to determine what supports would be most needed in a programme designed to assist in their transition to third level. One of the respondents was a student who had dropped out of college and not returned but is hoping to re engage next year with help from the DSS, one is a current UCC student who had started in another third level institute and dropped out after failing first year and a further two of the interviewees had to repeat modules or a full year. Their insight was invaluable into the reasons, in hindsight, they felt they had not done as well as they had hoped. The other four students, although not failing modules completely had to repeat essays and exams and get extensions and dispensations at numerous times. All respondents admitted to struggling in certain areas due to their AS and not sufficient support or preparation. This section is purposefully rich in detailed quotations from the interviews as the researcher is eager to let the students suggestions make impact. Accordingly, the objective of the NLN to design a programme which is person centred and reflective of student experience is being met. It gives a voice to the students with AS and recognises the value of their contribution.

The findings have been outlined under the following headings;

- Transition to Third Level
- What Supports are Currently Received
- Social Skills - Academic
- Social Skills
- Discussing the Diagnosis of Asperger's Syndrome
- Anxiety and Depression
- Organisation and Motivation
- Using the Library
- Perfectionism

Transition to Third Level

Five of the eight interviewees mentioned that they found the learning environment very different than secondary school.

College is a new way of learning for all students. However for a student with AS it can be significantly more difficult to organise themselves to learn in this new environment.

"I just did not know what was expected of me. Some of the lectures were very abstract. I got a reading list with about 30 readings and nobody told me that I was not expected to read every bit of every book on the list."

Another student also highlighted that:

"lecturers were not always direct in what they wanted. Stuff mentioned in class was not always relevant"

These excerpts concur with reference in the literature which supports that students with AS have difficulty with the 'Hidden Curriculum' (Myles and Simpson, 2001, Graetz and Spampinato, 2008) The expectations of students in third level can be vague, particularly in larger classes. A pre college support programme could assist students with AS to understand the requirements of them and teach them how to decipher specific instructions. It is apparent from the research that students with AS need more explicit explanation of what is necessary for them to succeed academically.

Another student said that he would have benefitted from being told it was acceptable to ask for help.

"I wish someone had told me I could ask a lecturer or email them if I needed clarification. Nobody told me this. I only overheard it near the end of the year. I was afraid to ask. I would have really liked if people made me aware"

This quote further emphasises the need to teach students with AS concepts which other students take for granted as being fact.

Student experiences in the first year at UCC were varied. However there was sufficient evidence to suggest that for students with AS, beginning third level can be a positive experience.

"I enjoyed the freedom of such a big environment and it was liberating in comparison to secondary school"

Two more of the students also had positive expectations of beginning college.

"I was looking forward to a new start and meeting new people in new surroundings"

"I was bullied in secondary school and I felt it was a good chance to leave all that behind"

This perspective is also highlighted in various research findings alluded to in the literature. In particular, Madriaga et al (2006) referred to the euphoria that students with AS experienced when starting third level as it was an opportunity for reinvention and to leave negative experiences behind them. This initial euphoria could be captured in a pre college programme and channelled into positive optimism to encourage students with AS to be confident and enthusiastic in their new environment.

What Supports are Currently Received

Of all the students interviewed, none of them received any form of individualised transition planning support when moving from secondary school to third level. This highlights a significant gap in the support services needed for students with AS in order for them to transition successfully. The literature review emphasises the importance of an effective transition plan to ensure success at the third level. This endorses the gap which the NLN have identified.

The majority of respondents received some support during their earlier education. These supports were mainly in the form of resource classes but there was a general theme emerging that they were not targeted enough to deal with AS specific issues.

A common theme emanating from the research was that parental support was of vital importance. Over half of the respondents, 6 out of 8, stated that their parents had researched the supports available in UCC and linked in with the Disability Support Service on behalf of the student. The participants appeared to be content with having this parental support and appreciated having a person to advocate on their behalf.

"only for my mother I would be even more lost. She is a great help."

"my parents motivate me. If I didn't have the support and encouragement from them then maybe I wouldn't even continue."

The majority of the respondents mentioned support received from the Disability Support Service in UCC. A subsidised computer was provided to three of the students as they had difficulty with handwriting. One student received a scribe service to record lecture notes.

Supports which are currently in place during exam time include extra time and a quiet, smaller room. The students expressed appreciation for this concession, particularly the separate room.

"The room is airy. It is a smaller, quieter room with fewer distractions. Trying to find your seat in a room of 400 people is very daunting. If you go up to use the toilet and then find it difficult to find your seat it can mean your train of thought is gone for the exam as anxiety overcomes you."

"I get social anxiety really easily so being away from other students in an exam is ideal. If I am looking around and see people leaving before I do, I get anxious."

A peer mentor from the Disability Support Service meets some of the students with AS individually throughout the week and helps with organisational skills, motivation and other skills that the student identifies. This peer mentor is a past student of UCC and has a diagnosis of AS. Three of the students whom I interviewed explicitly expressed their appreciation for this service and saw this mentor as someone they could trust if they had a problem.

The researcher concludes that strategic links with the Disability Support Service is of utmost importance for the NLN. If they develop a pre college programme, it should include introducing the student to the DSS and explaining the benefits of utilising the services they provide.

Social Skills – Academic

One of the main clinical characteristics of AS is social skill deficits. (Attwood, 2000) Indicative of their diagnosis, a number of respondents have had trouble with social skills in lectures.

"I find it really hard to answer questions in class. Even if I fully know the answer, being put on the spot makes it really hard for me to think properly. I get anxious and then can't think."
"Sometimes the noise at the start of lectures with everybody taking can make me retract into myself and then I can't regain my focus."

Attention span was another difficultly expressed by a number of the respondents.

"it was difficult to pay attention in lectures as some rooms were so big and there were so many people"

The environments in lectures may be diverse and different from the secondary school setting. There may be a variance in class size, lecture room size, teaching techniques and mix of people. A pre college programme could assist students to be aware of this variety and identify subsequent issues which may emerge. In helping students to self identify potential problems, it can make them aware of their limitations and empower them to develop coping strategies. The pre college programme should facilitate trial runs in a lecture room setting or run with a concurrent academic module to provide students with an opportunity to put the strategies into practice.

In terms of course work, issues which emerged from the research as being problematic were presentations and group work.

"I don't like speaking publically and being in the spot-light"

"I'm terrified of giving presentations and the feeling of being judged. I present worse than I should because I get so nervous. I've always wondered whether it would be possible for me to get used to it and get a little confidence. I'm very insecure about my abilities though"

The issue of group work emerged in many of the dialogues. Some of the students said they were grateful that group work was never expected of them yet in their coursework. Interestingly, the reasons for not liking group work were varied.

"I do not like it because I hate having to depend on others to do work well so I can get a good mark. I am not in control and I generally cannot trust other people to do a job that would be the quality I would be satisfied with so sometimes I end up doing all the work for the group. Sometimes other people are not reliable and do not have work done when they say they will"

Another student mentioned a different reason for not liking group work.

"having the extra pressure of letting down the group makes me very anxious"

A third respondent stated her reasons for not liking group work as follows;

"I like to know exactly what the group expects me to do. I feel uncomfortable if the work is not allocated right and people do not know exactly the parts they need to do. Because of my bad social skills I find it hard to ask people to clarify the expectations of me in the group and I find it too difficult to allocate work to other people as I don't communicate things clearly enough. It is so hard in a group because sometimes everyone is talking at once. I just tune out"

However one student welcomed the prospect of group work and saw it as a way to get to know fellow classmates.

It is interesting that although all interviewees have the same diagnosis, there is a variance in the way their condition manifests itself. The above opinions on group work provide valuable illustration of the variation in how a students with AS will experience college life. This is evidence to support a programme that is person centred and individual to the student being supported. An area where one student with AS will struggle, is an area where another student may flourish. The diversity of support needs of students with AS is supported by research in the area. (Madriaga et al, 2006; Blamires and Gee 2000; Gleeson et al 2010)

Social Skills

In a non academic context, social skills were a worry for many students on a personal level. A general theme throughout the interviews was that there was an initial concern about having trouble making friends and being isolated in social situations.

"I was worried I would be isolated and left on my own all day with nobody to talk to."

"I am really uncomfortable around new people and was so anxious about meeting so many strangers"

"One of my biggest fears was being left out, and that has proved broadly accurate"

Some of the students felt they were lucky as they had a friend from secondary school in UCC and this helped them to settle in better.

One of the interviewees suggested that if they were in a pre college supported year that perhaps

"it would be a good idea during a pre college year to be allowed to join societies and groups in college. I wanted to join in first year but I was afraid and didn't even know where to go or who to ask. It was too daunting in Fresher's week to ask questions. Maybe if there was help in that area, even if someone just gave me an idea of what clubs and societies there was, where to go and what questions to ask. I think that would be a good help"

When the research explained the nature of a pre college programme to one interviewee, he felt that it would be a good opportunity to have

"More chances to work with people and develop better social and communication skills."

As reported in the literature Myles (2002) and Mesibov (1984) suggested that teaching social skills in a group setting allows participants to develop new skills while using these skills to form relationships within the context of the group. Attwood (2000) suggest that social groups provide an opportunity to learn and practise a range of advanced social abilities.

One student referred to life skills as important to be included in a pre college programme.

"I think it would be good to get some idea how to manage money and eat healthy for cheap and do laundry and just general look after myself away from home."

These skills, although not part of education per se, can be valuable lifelong social skills to acquire which would impact on all aspects of the person's life into the future.

Ensuing from the above accounts, a social skills element to the proposed programme is of paramount importance. If the student can improve on their social skills it can have a positive lifelong impact.

Discussing the Diagnosis of Asperger's Syndrome

There was a variance in responses to the issue of making the diagnosis of AS known to lecturers and fellow students.

"I am very concerned that I will be labelled and judged as I have been labelled and judged before. Having one designated person in the department as a contact if something is going wrong would be beneficial but there can be lack of understanding. People can underestimate just how difficult things can be for me. They might feel I am not putting enough effort in."

However, in contrast, one respondent stated that:

"I think it is very beneficial for lecturers to know especially when you have that panic like oh my god I don't know what's going on, you can ask for help"

The mixture of responses can make it difficult to decide the most appropriate intervention. There are acknowledged benefits of disclosing the disability, particularly to lecturers. However some students did not want to be seen as different. Ultimately it is a decision that should be decided exclusively by the student. This was supported by the majority of the respondents.

"I think it is 100% up to the individual student to make their classmates and lecturers aware. You are giving the power to the students to inform who they want. Alot of people might guess anyway but I like to be in control of who knows."

There is merit from this research that a programme should assist students to disclose their condition if they desire by empowering them with the confidence to discuss it.

Anxiety and Depression

Anxiety and depression was a theme which was mentioned across almost all interviews.

"I would get so worried about a deadline that I would block it out and then get sad when I had to repeat the module."

Another student commented that;

"I would get so anxious and panicky that I would stay in my room for days. I think I was depressed at many points."

This anxiety and depression can lead to students withdrawing and not achieving their potentials. The difficulties a student with AS faces because of their condition can be exacerbated by anxiety, depression and subsequently tiredness, lack of motivation and inability to think clearly. Many of the students expressed concern that their AS symptoms need to be controlled or anxiety can be triggered.

A frequent theme which emerged from the interviews was that the students felt they needed assistance to acquire self help skills. One student said:

"I wish I could help myself. Instead I get frustrated with myself for letting things build up on me. I should be able to know when things are getting to me and remove myself from that environment"

This self identification of support needs could be used in a pre college programme as a means of preparation. Self identification can be empowering and enable the student to determine their own coping strategies when things get tough. According to Lazarus and Folkman (1984) coping

strategies include any attempt or effort to manage stress, regardless of how well it works. Judge (1998) explains this further by describing coping strategies as efforts to amend the cause of the stress and attempts to regulate emotional responses to the stressors.

The research found that many of the students would like to be able to learn to deal with anxiety levels in order to prevent it getting worse and leading to depression. Interestingly, some of the students identified their own self help ways of dealing with this anxiety. However some other students felt they needed more skills in this area.

"stress and anxiety can be a vicious cycle. If I could learn to deal with it I think I could stop it getting worse and worse."

"I can partially prepare myself for anxiety if I feel it building. I use the GTD method when I feel an attack coming on."

The interviewer asked the student to describe a GTD method as it was something that was unfamiliar. The student went on to say that it was something he had seen on the Internet and it was a way for him to control his anxiety.

"It stands for Getting Things Done. By planning I can reduce the feeling of not knowing what I still have to do. The fear of anxiety motivates and pushes me to get things done. The more structured and predictable I can keep my day the less stress I bring upon myself."

Many of the students who were interviewed did not appear to be too concerned with the stress and appear to have an understanding and acceptance of it as a symptom of their condition.

"I have experienced enough attacks to know they don't often leave lasting impact"

"If I do things weeks ahead of time, I can significantly reduce the amount of anxiety I feel, which causes anxiety attacks to decrease"

Although for some students it is not problematic, there was significant worry among the respondents about dealing with anxiety. The NLN could facilitate self reflection during the pre college programme and assist the students in dealing with this anxiety. The NLN can also develop strategic alliance with mental health services in order to refer students for more appropriate intervention if needed.

Organisation and Motivation

Unanimously, an issue which emerged from all interviewees was lack of ability to organise themselves effectively.

"I have real issues with organising myself. In school if you didn't do something there was a direct repercussion. In college there is none of that. The sense of freedom becomes

overwhelming. Sometimes I don't even know I have missed deadlines. I think I would like a programme to try help in this area"

One student detailed this

"I had terrible time management and organisation. I had to teach myself what time was. It isn't instinctive. I was always late for lectures. Because it was so different to school and I often had a few free hours in the middle of the day, I would get lost in my head and forget the time"

The importance of being able to organise oneself and utilise your abilities is of vital importance for all students. However for a student with AS, these skills may need to be taught and practised as they are not intrinsic. This quote reflects the difficulties experienced by a student with AS who lacks organisational skills.

"...organisational skills are vital for any programme for AS students. If you are not organised everything else will suffer. It is nothing to do with intelligence. You have to balance that intelligence with being able to utilise it in the right way. You can be more intelligent than everyone in your class but you have to be able to put things on paper to get results in assignments and exams. I could have the most perfect essay in my head but I need to be able to be organised enough to put it down on paper and submit it."

Similar experiences were detailed by another student

"Even living a minute away from lectures I didn't make it on time to college. My organisation was appalling. I couldn't understand how everyone else just got things done. I just stopped going in. Avoided it. Didn't do any study. Just ignored it. I was really enthusiastic starting new things and printed out loads of notes, did loads of research but that level of enthusiasm wasn't sustainable."

Another student commented that:

"Planning ahead is very difficult for me. I need help to prioritise one thing over another"

When asked to make a suggestion of what would help, that student highlighted the support received from the Disability Support Service peer mentor.

"we can write out collective deadlines in the order that they are due. I think writing out a pattern of deadlines and giving a visual representation of what needs to be done is a great support."

Another student reflected that *"I am still in the process of working out what works for me."*

When asked what would help with this process, the interviewee stated that it would help to

"*write out a list of all the things which I am having problems with and then identify and be aware of my own difficulties and come up with ways to deal with them."*

Another student concurred with this and highlighted the importance of being organised.

"The biggest problem has been that my course is very self-directed and I find it hard to organise time and develop a plan for my work and that is frustrating. I think having a well thought out and straight-forward plan from the start would be a great help."

Accordingly, a pre college programme could focus on preparing the student with AS to allocate work based on deadlines and in order of importance. Acquiring the skill to make weekly and monthly deadlines and a system of prioritising work would be beneficial for the students to learn in a pre college year. Learning to adhere to schedules and deadlines would prevent build up of work and potential resulting anxiety and stress.

A correlated word which emerged in many of the transcripts following an analysis of the data was motivation. The issue of lack of motivation was expressed by a number of the students.

"There is at least one day a week where I stay home and do nothing. It gets too much. I need a break. I get tired easier because of stress and stuff. The more I leave things the less motivation I have to start"

"I lose interest and momentum and then get panicky. I found that the longer I spent out of college, the more anxiety I felt about the prospect of returning I would need my mother to motivate me to go back to college after a few days."

Motivating students with AS can be difficult, particularly in subjects they like least. (Attwod, 2000) However, from talking with the students, the researcher concludes that if organisational skills were improved it would subsequently impact on motivation. There was a discernible desire to succeed from the students.

Using the Library

Six of the eight students had problems using the library. Although some of the students noted that with electronic databases and resources the use of the library is not essential, others said they would like to successfully utilise it.

"I didn't go into the library in the whole of first year as I couldn't work out what to do. There is support available but it needs to be done as a sequence to walk people through step by step and not just a verbal workshop with too much information. There needs to be specific walk through of how to print, how to take out a book, how to find a book...sequencing is a problem because of my AS so even finding books can be difficult."

Another student who used a library skills workshop which was organised by the college said that

"Visual backups would be great so I could access the information again when needed. I went to a workshop but once someone told me how to do something, and once it is spoken it is gone. It needs to be broken down step by step. Even the organisation of going to the library. You need your card to get into the library and take out a book. You need money to buy a photocopy card. I would forget these things so a step by step visual guide would be useful"

The students have identified specific ways in which a pre college programme could assist in them successfully using the library. Strategic links will need to be made between the NLN and UCC to enable them to use the library facilities in order to demonstrate practical skills to the students.

Perfectionism

The problem of perfectionism was highlighted strongly in two of the interviews and touched on indirectly in a number of others. This attention to detail can be beneficial in certain cases but can be detrimental in others. This is reflected in the following extract of an interview.

"Perfectionism can be a strong part of AS, not for everyone but for some. Putting work on paper doesn't come out perfect. I will focus on getting it so perfect that it impedes my time as everything else will be put on hold to make sure each part is perfect. It can even stop me starting things sometimes as I am afraid to put anything on paper as the perfect essay in my head gets ruined the minute I put in on paper and realise it is not perfect."

Another student also highlighted the problem of focusing on getting things perfect.

"I am a sort of a perfectionist in terms of how I learn something. I need to know every detail before I feel confident with the information."

In light of this, a pre college programme should facilitate the student to recognise the disadvantages of perfectionism. By practising assignments and looking at case studies, it could assist the student in understanding that expectations for college assignments and exams are different than the experience of learning in secondary school. In many cases, depending on the subject, you are judged on your ability to use the information to make a point. A programme to teach students with AS to realise that you can rarely have a perfect answer is valuable and that complete perfectionism is not attainable. There is a whole shift in what is expected of you in third level which is not explicitly explained by anyone. The expectations and shift is taken for granted and inferred. This shift in thinking is in line with the sociological theory of the Hidden Curriculum, highlighted in the literature, which can be difficult for a student with AS to comprehend without being unequivocally taught it. A pre college programme can make the transition for students with AS easier and more successful by explaining what is required of them and how to utilise their abilities to do well in assignments and exams. There is merit in teaching students with AS how to find the balance between striving for perfection and working at a manageable pace to reach deadlines.

Linked to the issues brought about by perfectionism was a theme which emerged about hyper focusing on a favourite subject. Many of the students said they found it difficult to dedicate time

to all subjects equally because they liked some more than others. There was a tendency for some of the students to focus on one subject to the detriment of the others.

One student suggested in the interview a method he uses to help himself to use his time effectively and not spend too much time on his preferred modules.

"I use a timer and work for one hour segments. I tell myself, I am going to give this one hour and then move onto another thing. If I have a lot of work to do, like an essay, I might give myself a one week limit for that subject and then force myself to move onto something else. I had to teach myself to be disciplined"

Having a study skills element to the pre college programme would be imperative based on these findings. Students need to learn how to organise their time effectively and how to prioritise deadlines and effectively need to be taught a new way of studying.

Overview of Key Findings

This study aimed to assess the experience of students with AS in third level with the view to using their empirical evidence and narratives to develop a pre college programme. The research came to conclusions through both a literature review and primary research carried out with the students with AS. From this data various themes emerged which portrayed significant factors which impacted on students experiences of third level and thus form the basis for the recommendations to the NLN.

The research found that there is significant requirement for a specific, targeted, individualised support programme for students with AS. The legislative background and educational policy in Ireland supports non discrimination of students with a disability and the ESPEN 2004 Act specifics that there should be provision in place in an education plan to ensure that education or training continues into adulthood. Smith 2007, Madriaga et al 2006 and Glesson et al 2010 which were highlighted in the literature all advocate an individualised support plan for students with AS to support their diverse needs.

The National Plan for Equity of Access to Higher Education 2008-2013 suggests that to target students with a disability a focused pre college programme should be utilised. The difficulties in transitioning to third level which have emerged from the literature and from the lived experiences of the students themselves could be offset by implementing the proposed NLN programme with particular emphasis on individualised support. The perspectives of the interviewees has highlighted the specific difficulties being faced by students with AS and thus can provide a

framework for the development of a programme. According to (Martin, 2008) achievement is most likely if systems can be in place from before the start of a third level course.

The literature highlights an innovative programme being run in the University of Connecticut which although is a pre college programme, it does include an academic module. It has become apparent from the research that his model of support programme would be beneficial to assist the students with AS to gain practical experience of genuine university life and apply the learning from the programme to an academic context. The issues which emerged throughout the interviews such as organisational skills, perfectionism, motivation, using the library and anxiety and stress could be tackled in a realistic environment if an academic module was run concurrently with the pre college programme. As identified in other research, a concrete academic module, together with the pre college support programme would be desirable.

It is desirable for the learner to try things out because of their potentially having difficulty with imagining new situations in the abstract" (Martin, 2008 pg 89)

The following section with examine the above findings in the context of making tangible recommendation to the NLN for use in the development of their proposed programme.

Recommendations and Conclusions

Conclusion

The issues highlighted in the interviews with students with AS are difficulties that many college students face. However, due to the diagnostic characteristics of AS these issues are exacerbated and deeper rooted.

One of the students highlighted that although their AS contributed to difficulties in college, there needed to be an emphasis on self responsibility.

"You can't use Asperger's as an excuse. Yes it is very difficult at times but I want to succeed and I will work hard to ensure that I can overcome any difficulty"

The researcher feels that this quote is reflective of the pervasive attitudes of the students interviewed. The students, by virtue of the fact that they are in third level, have an inherent ambition to succeed. This research found that, in general, the interviewees are aware of their social skill deficits and mindful of the difficulties that they face in academia due to their AS and were truthful in their reporting of their experiences in university. The students with AS who were interviewed are willing to try to overcome these obstacles and appear open to any support which would be available.

The literature highlights the need for a targeted programme which meets the specific needs of the students it supports.

The review of the legislation and literature coupled with interest from the majority of students interviewed make the proposed NLN pre college programme a feasible development opportunity.

Recommendations to the National Learning Network

The primary rationale for this research was to make recommendations to the NLN on what areas would be essential for a pre college programme for students with AS. The analysis of the interviews with the eight students and the review of the existing literature support the following recommendations being made. The aim of the recommendations is to form the basis for the development of a pre college programme to assist students with AS in their transition to third level and equip them with the skills to succeed in their new environment.

If the programme is to be initiated the following recommendations are advised based on the research undertaken. These recommendations are based on the literature and analysis of the key findings. However, the recommendations are a generic overview of what the researcher suggests

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being included. As highlighted throughout the study, the programme should be individualised to the needs of each student. Consequently, the researcher advises that the NLN look at the findings section as a guide to inform practise and then adapt the course to individual need.

The general recommendations proposed are;

1) The research suggests that there is an apparent need for this programme and that in general there is positive feedback from students with AS about the merits of participating in it. Evidence from the research confirms that it is only with retrospective observation that the full benefits of this proposed programme become apparent.

Parental support was highlighted on many occasions, in many contexts as being essential to the student. The consensus from the interviewees was that there would need to be parental support for the programme, as generally the main burden of extra cost would fall on them. The researcher deduces that the views of parents may influence the take up rate of the programme. Consequently, it would be useful to run open evenings on the programme for parents and prospective students which include input from AS students who have experienced the difficulties which college life brings. By hearing evidence of the lived experiences of students with AS it can highlight the necessity for support and put emphasis on the advantages of a pre college support programme.

2) One of the main themes emerging from the narratives is that students struggled with organisational skills. Students mentioned that this led them to having difficulties with assignments and deadlines as they struggled to manage their time and workload. In order to effectively teach skills to allocate work based on deadlines and in order of importance it is suggested an actual academic module should be part of the pre college programme.

The researcher proposes a programme which includes an academic module run simultaneously similar to the system run in the University of Connecticut referred to in the literature.

By completing one module it gives students the opportunity to practise study and research skills, learn how grading systems operate, manage workload and prioritise their deadlines. It would also facilitate the pre college programme to do group work on specific problems which were encountered. These issues are ones which students identified when asked what supports they needed and which the literature identifies as essential. If strategic relationships are developed between the NLN and UCC, it may be an option instead of complete deferral of their place for a year in order to complete a pre college programme. The researcher feels that the ability to do a

concrete module which will add towards the final degree would motivate the students with AS to actively participate in the practise of study and research skills. By completing one module it will allow students to go to lectures, interact with fellow students, complete assignments and get a pragmatic view of college life. This practical experience will allow them to self identify problems which emerge and help the NLN programme to identify individual needs. By completing an actual module it also takes away the daunting fear of the unknown for the student as they begin first year. A person with AS can find it difficult to imagine things in the abstract and so this practical experience is imperative. By having lectures it gives the students opportunity to interact with lecturers and can empower them with the ability to advocate for themselves if they need academic assistance. It also gives an opportunity for students to become accustomed to using the library, doing group work or presentations, knowing the services which exist to help them and becoming familiar with their new environments. As a student suggested in the course of the interview, it could also give the student opportunity to mix with peers and join a society or group on campus.

If it is not feasible to run an actual UCC academic module, it is recommended that an accredited FETAC course, or equivalent, is built into the programme. The researcher considers that having to undergo actual academic content in order to learn the skills identified in the research is imperative. In order to maximise the learning potential in this pre college year, it is crucial to have hands on academic experience. This recommendation encourages the student to develop a practical solution based approach to structuring workload and organising deadlines whilst undergoing this pre college year. It is expected that this will assist them to acquire the skills which have been identified in a more meaningful way in comparison to learning them theoretically and not having the opportunity to apply them in a practical academic setting.

3) The research from the literature is unanimous in its suggestion that a specific, targeted programme for each student is necessary. The NLN programme can work with individual students to tailor a package of support and allow the student to self identify what supports they require. Once supports are acknowledged the programme can encourage students to identify their own strategies to manage difficult situations which arise for them. This self identification of support needs could be used in a pre college programme as a means of preparation. Self identification can be empowering and enable the student to determine their own coping strategies overcome difficulties which arise in the course of third level life.

4) A general education of what is expected of students in third level would be very useful. Many of the students expressed concern that they were just not sure of the expectations of them. As identified in the research, both in the literature and in the qualitative accounts, the sociological theory of the Hidden Curriculum can be challenging to students with AS. Even the simple premise of knowing you can ask for help can be complex for a student with AS. Myles and Simpson (2001) argue that students with AS are at a disadvantage because they do not understand the Hidden Curriculum. As a result they inadvertently break the rules associated with it. Instruction and interpretation of hidden curriculum items such as learning social rules and norms and explicit instruction on expectations should be an integral part of a pre college programme.

5) Help with managing day to day living is an important part of success in third level for a student with AS. Tasks such as budgeting, shopping, cooking and self care should be discussed in this pre college year in order to prepare the student for successful independent living. If the student was proficient in these areas it may help in organising their overall time and increase their general quality of life whilst in college. This holistic approach would assist the students to succeed academically but also give them lifelong skills which would benefit every aspect of their lives into the future.

6) It is recommended that the NLN utilise other agencies to develop partnerships to provide a comprehensive support programme. Having strategic links with the Disability Support Service in UCC is of crucial importance for the NLN. Throughout the research, the students acknowledged the support they received from the DSS. The pre college year should be used to develop an individual support plan which could be used as a guide for the DSS to continue to support the student throughout their college years. Another internal link with UCC which is recommended is with the Occupational Therapy department. The Trinity College Dublin disability support service and its Unilink service with the OT department has been acknowledged by ASPIRE, the Irish Asperger's Syndrome Association in their consultation to the National Strategy for Higher Education (ASPIRE, 2009) as very useful in supporting students with AS. However they indicate that this support should be provided and made available by all third level institutions in Ireland. This is an opportunity for the proposed NLN programme to follow in its achievement. Involvement from an OT can assist in developing strategies with the student to overcome practical issues and difficulties associated with their condition.

The research also highlights that the issue of anxiety and depression is prevalent among the students with AS. Developing links with agencies specialist in prevention and treatment of these conditions can assist the students as the NLN programme co-ordinator can refer and advise the student as necessary.
These strategic links can offer a more comprehensive package of support for the student with AS throughout this programme.

7) Emanating from the literature is the need to educate service providers Madriaga et al (2006) concluded that many of the barriers faced by students with AS were not a result of their condition. They were perpetrated by poor practise and lack of disability awareness in the institutions. The NLN could examine the potential to offer consultancy to the institutions in UCC and other third level institutions to facilitate best practise in supporting students with AS.

8) The researcher also recommends that there is post college support for students with AS because although it wasn't explicitly relevant to this study, a number of students did express concern that once college is over they have to face new challenges in the workforce. Further research similar to this study is recommended in this area so the strategy for a post college programme is also driven by the opinions of the students with AS. A post college programme may involve advice on completing further study, guidance and assistance in applying for employment and skills and strategies for succeeding in the labour force. Knowing there is prospect of employment after education may act as a motivator to students with AS throughout their time in college.

Authors Comments

These recommendations in conjunction with information detailed in the narratives from the student interviews aim to contribute to the development of comprehensive support programme for students with AS into the future.
However, because the needs of students with AS are highly varied, recommended interventions can only be determined by evaluating what works successfully for the individual. Consequently it is of utmost importance that any support plan is devised to reflect the elements of the programme recommended above which suit the individuals need.
This programme is in line with the legislative context and social policies in Ireland concerning people with a disability in education. There is considerable interest in the programme from

students with AS based on their responses throughout this study. This research, along with other pertinent studies suggests that a pre college programme is advantageous in assisting students to meet their potential and overcome the difficulties they may face as a result of their condition.

Based on this research, there is concrete evidence to support the proposed programme the NLN aspire to develop. There is substantiation in the literature and from the students with AS that it would be beneficial in providing inclusive support.

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Appendix I

Asperger's Syndrome

This section will provide a brief outline of the characteristics of Asperger's Syndrome. It will act as a guide for people reading this report who have no experience or understanding of the features of the syndrome. This description only acts as a short outline and does not convey the complexities and varying aspects of Asperger's Syndrome.

The following outline is constructed from information in Attwood, T. 1998 Asperger's Syndrome. London: Jessica Kingsley. Tony Attwood, a psychologist, is an author of several bestselling books on the topic.

The main clinical features of Asperger's Syndrome are:

- Lack of Empathy
- Naïve, inappropriate, one sided interaction
- Little or no ability to form friendships
- Pedantic, repetitive speech
- Poor non verbal communication
- Intense absorption in certain subjects
- Clumsy and ill coordinated movements and odd postures

Attwood breaks these features down into individual chapters in the book as follows

1) Social behaviour – the diagnostic criterion related to social impairment includes the following aspects a) inability to interact with peers, b) lack of desire to interact with peers, c) lack of appreciation of social cues and d) socially and emotionally inappropriate behaviour. Another of the diagnostic criteria explores non verbal communication which reflects in social behaviour and includes a) limited use of gestures, b) clumsy body language, c) limited facial expressions, d) inappropriate expression and e) peculiar, stiff gaze.

2) Language – diagnostic criteria in this area includes a) delayed development, b) superficially perfect expressive language, c) formal pedantic language, d) odd prosody, peculiar voice characteristics and e) impairments in comprehension, including misinterpretations of literal/implied meaning.

3) Interests and Routines – This aspect of the condition focuses on the presence of narrow interests and repetitive routines. Having a narrow interest becomes problematic as it leads to the exclusion of other activities, repetitive adherence and has more rote than meaning. These pursuits are often solidarity, idiosyncratic and dominate the person's time and conversation.

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4) Motor Clumsiness – Research suggests that 50 – 90 per cent of people with Asperger's Syndrome have problems with motor co-ordination. This is apparent in a variety of ways and can cause problems with balance, handwriting, limb co-ordination when walking, ball skills, low muscle tone and manual dexterity to complete simple daily tasks.

5) Cognition – People with a diagnosis of Asperger's Syndrome appear to have difficulty conceptualising and appreciating the thoughts and feelings of another person. A person with AS may have difficulty with flexible thinking, which leads to rigid ideas and thoughts which cannot be easily changed. However cognition can be an area where a person with Asperger's will excel. A person with AS can have above average intelligence and an excellent memory and attention to detail.

6) Sensory Sensitivity- This can involve sound sensitivity, tactile sensitivity, sensitivity to taste and texture of food, visual sensitivity and sensitivity to pain.

Appendix Two

UCC Science Shop

Linking Communities & University Research

Science Shop Research Agreement



ucc

Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Name of student(s):	Sinead Slattery
Name of civil society organization/community group:	National Learning Network
Date:	24 November 2011

An agreement between **National Learning Network** and **Sinead Slattery, Master in Social Science Third Sector student,** University College Cork, Cork.

This agreement relates to arrangements agreed between the student and the group for the execution of a research project entitled: **An exploration of needed support for people with Asperger syndrome or High Functioning Autism to successfully complete Third Level Education.**

1. It has been agreed that **Sinead Slattery** will carry out research on behalf of and in participation with **National Learning Network** as follows.

    - Conduct a literature/policy review on the topic documenting best current practice in place in Ireland and abroad.
    - Undertake qualitative primary research with in-depth, face-to-face interviews with adults who are or have been third level students in Cork and who have a clinical diagnosis of Asperger syndrome or High Functioning Autism.
    - The research will comply with guidelines and rules of the Ethical Committee in UCC.

2. The time of the academic supervisor of the student undertaking the research will normally be provided without charge as part of the student's degree course at the University.

3. The University will provide accommodation, the use of equipment, the services of technical and other supplies to the extent that is normally provided for internally based student projects. Where the provision required for the timely and efficient execution of the project exceeds the normal allowance for student projects or exceeds the host department's budget, the client may be asked to pay for such provision or to join with the University in securing provision from a third party source. No costs will be incurred without prior agreement. (These additional provisions will be listed in an appendix at the end of the Agreement if deemed necessary).

4. The name of the student(s) will be listed below. The names of the students, the academic supervisor, or the University may only be used after obtaining prior approval. Permission to refer to the University will not be unreasonably withheld.

5. The copyright, or any other intellectual property rights, created by the project will rest with the University. Free and full use by the Client Group for the purpose declared when the project was initiated is agreed in advance. Use for any further purpose(s) will be for negotiation and approval on a case-to-case basis. Permission will not be unreasonably withheld.

6. Use of the project report in other than its complete form will be checked with the University in reasonable and sufficient time before the intended date of such use to allow discussion as to the accuracy or suitability of the modified form.

7. Students will normally carry out the project. 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.

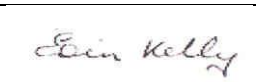
8. Upon completion of the project the student (as well as completing the requirements of his or her University course) will be responsible for providing the group with a completed copy of their project report. The student shall provide them with the completed project report within a reasonable amount of time, not more than two months after submission of the dissertation to the University.

9. All parties agree that upon completion of the project, the research report will be placed, with the approval of the course tutor providing it reaches the requisite academic and presentation standards, on the UCC Science Shop website: http://scienceshop.ucc.ie.

Completion date of research report to Group is:	08/06/2012

Student dissertation submission date:	08/06/2012

Signed on behalf of (the name of Client Group)

Signature:	
Print Name:	Eoin Kelly
Title/Role in Group:	Area Manager
Date:	28/11/11

Signed by student(s)

Signature:	
Print Name:	Sinead Slattery
University Course and Year:	Master of Social Science Third Sector
Date:	28/11/11

Appendix Three

To whom it may concern,

My name is Sinead Slattery. I am a Masters student in the Dept of Applied Social Studies in UCC. I am undertaking a thesis in conjunction with the National Learning Network. The research they want completed is to identify the supports needed for students with Asperger's Syndrome to complete third level education. On completion of this project, it is envisioned that the results will be an accurate reflection of the student experience and provide a better understanding of what supports are needed for students with Asperger's Syndrome in order for them to successfully complete Third Level Education. The researcher aims to provide a piece of work to the National Learning Network with the view of them developing a pre college programme for students with Asperger's Syndrome in Cork to prepare them through practical applied experiential learning

I am proposing interviewing students with Asperger's Syndrome who are currently in UCC to get their views on their college experience and identify the potential supports to assist students with Asperger's Syndrome to complete third level education.

I am looking for your help to get an insight into the college experiences of students with a diagnosis of Asperger's Syndrome. The interviews can be conducted at a time and place which is convenient to you. The research findings could lead to a potentially improved college experience for future students with Asperger's Syndrome. Every effort will be made to ensure your confidentiality of any identifying information that is obtained in connection with this study

If you are interested in participating in this research I would be grateful if you can contact me via your tutor, the Disability Support Service or directly at 110221687@umail.ucc.ie

Many thanks

Sinead Slattery

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Appendix Four

Interview Schedule

I will initially explain the research and pre college programme NLN are proposing.

Did you have support in secondary school? Did you get any preparation/planning to assist in your transfer to Third Level?

Did you have any initial concerns before beginning U.C.C? If so what were they?

Did you research the supports available in UCC for students with Asperger's Syndrome prior to starting college?

What were your initial reactions to UCC?

How would you describe your experience of college? For example was it a positive experience or do you feel it was a negative experience and why?

How would you describe your social experience in college? For example did you meet a lot of new people?

Did you/Do you use the Disability Support Services available to you? How were you made aware of them?

What situations do you feel you need support with? (Probing may be used at this point to get more detailed descriptions)

Are there areas where support is available but you do not feel it is applicable to your needs or the needs of other students with Asperger's Syndrome?

Would you use a pre college programme if it were available? Why would you use/not use?

What areas do you think are vital to be included in a pre college programme for students with Asperger's Syndrome?

Do you think it would help if your lecturers and classmates had more awareness of Asperger's Syndrome?

Is there anything else you would like to contribute? Is there any other areas of support you think would benefit you or other students with Asperger's Syndrome?

Appendix Five

Participant's Consent Agreement

1. I am aware that my participation in this interview is voluntary.

2. I understand the intent and purpose of this research.

3. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.

4. I am aware that the interview will be recorded using a dictaphone and understand that this recording will be destroyed within a safe time frame of the project completion date. (6 months after completion) Therefore, I am willing to allow the interview to be recorded.

5. I am aware that this recording will be transcribed after the interview and that this transcript will also be accordingly destroyed within a safe time frame of the project's completion. (6 months after completion)

6. I am aware that the information provided may be used in submission for funding by the National Learning Network to secure subsidy for a pre college programme. The National Learning Network may use the findings in information documents relating to the programme.

7. I am aware the project, and therefore the data produced, may become available in the School Off-Print Library and/or the Boole Library on University College Cork campus.

8. The data gathered in this study is confidential with respect to my personal identity and group identity, unless I specify otherwise

9. If I have any questions about this study, I am free to contact the student researcher.

10. I am aware that I may at any time withdraw all data collected from the interview prior to the submission of the project.

11. I have been offered a copy of this consent form that I may keep for my own reference.

12. I understand that disguised extracts from my interview may be quoted in any subsequent publications if I give permission below:

(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_____

I have read the above form and, with the understanding that I can withdraw at any time without having to express a reason, I consent to participate in today's interview.

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Participant's signature:
Date:
Interviewer's signature:

Anonymity Issues

I can certify anonymity and confidentiality to all the research subjects in respect of not revealing their names. However due to the small number in the target group and collaboration with the Disability Support Service in UCC, there may be some identifiable features in their interview responses. Respondents will be given the opportunity, if desired, to read the final findings before publication and retract or amend quotes or opinions.

The recordings of the interviews will not have any reference to the names of the students involved and will be held in a secure place until six months after the research is completed (to facilitate verification if required) I will then destroy all recordings and transcripts

I can ensure all information is only used for the intended purpose and not shared with any third party except for those stated in the consent form.

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