"It's all about moving forward": An evaluation of student experience on the Inclusive Learning Initiative, Maynooth University

December 2013

Fergal Finnegan

Acknowledgements

Executive summary

The Inclusive Learning Initiative and the research

The report was commissioned in order to document and explore the experiences and of the students who are currently participating in the Inclusive Learning Initiative (ILI) at Maynooth University. The ILI is a pilot project, launched in 2011, which is seeking to make higher education more accessible for students with intellectual disabilities.

The study documents the challenges, supports and benefits of the ILI from the students' point of view. The findings are based on qualitative research (in-depth semi-structured interviews with all the ILI students, observation in the field and desk research). The data was analysed in a series of stages using grounded methods and the findings detailed here emerged through the thematic coding of content and narrative analysis.

This report is one component of a number of interconnected but distinct research projects evaluating the value and efficacy of the ILI project through consultation with MAYNOOTH UNIVERSITY and ILI staff, external stakeholders, ILI volunteers and the students.

Main findings

The data indicates that, from the students' perspective, the project has been very successful. The students believe participation has been beneficial for them in a variety of ways; most notably in increasing their sense of confidence and independence and creating opportunities to forge new relationships and build wider social networks. Attending university is valued by most of the students because they think going to college is now a normal part of the lifecourse, a source of family pride and an important shared experience between siblings. The students also value learning new things and several students discussed the role of their studies in enhancing their future occupational opportunities. Several of the students think college has helped them become more mature.

Nevertheless, the students did face a number of academic and social challenges in making the transition into third level education and in 'staying the course'. The main academic concerns

related to assessment and working through difficult material and the major social concerns all relate to building durable peer networks. These difficulties were overcome through personal determination and drawing on a range of formal and informal supports.

The key supports identified by the students were the ILI Learning Facilitator and other ILI staff, the help given by volunteers who have joined a programme established by the ILI, support from Maynooth University academic staff and the informal aid offered by peers, families and community members. According to the students this network of supports has been crucial to their success.
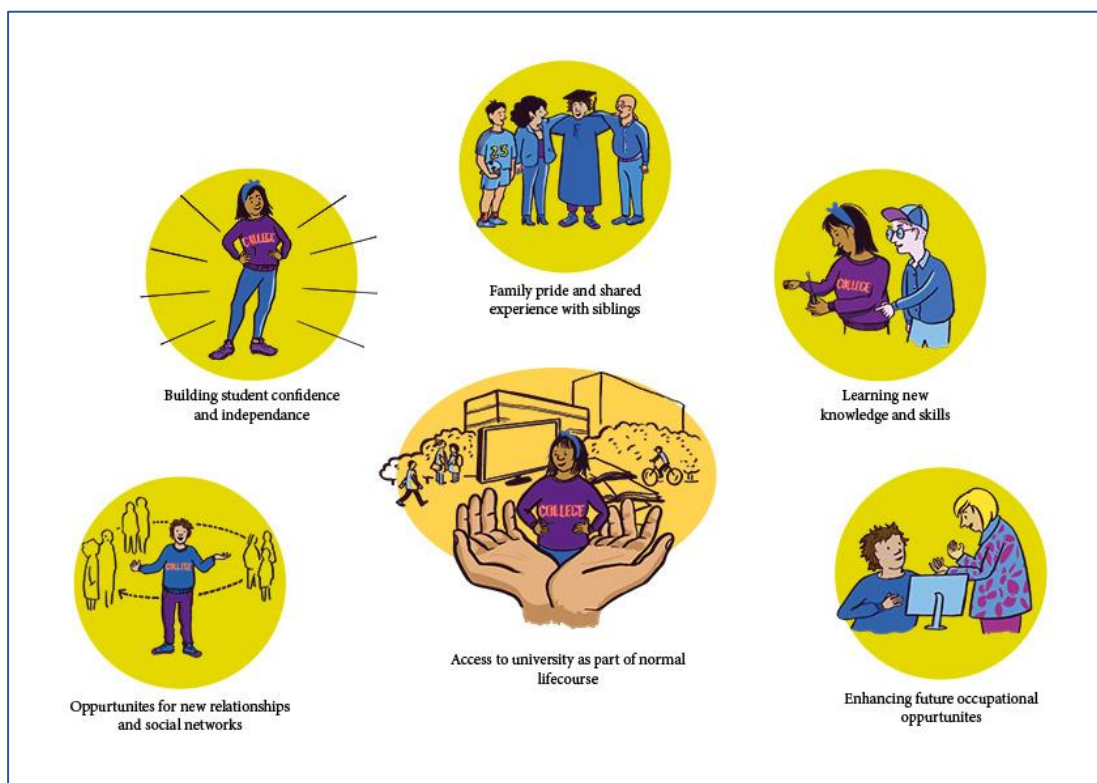
Figure 1: key themes of inclusive education

The field research and the student interviews strongly suggests that the ILI has accumulated a body of knowledge and developed a range of practices which could be very valuable in developing a more fully inclusive system of higher education in the future. The data also suggest that individualised support using peer networks of collaborative learning provides a very secure foundation for effective inclusive learning and pedagogy. Some of the implications for this are also briefly outlined in the study and the data is compared to research on student experience and inclusive education in other institutions and countries.

The report highlights potential issues for the ILI in the future – in terms of student concerns, the institutional visibility of the initiative and various modes of student engagement and identification with the project – and concludes with a number of recommendations.

Disclaimer

The views, opinions, findings, conclusions and/or recommendations expressed here are strictly those of the author and do not necessarily reflect the views of Maynooth University or the Inclusive Learning Initiative. Any errors and omissions are the author's sole responsibility.

Contents

Chapter One
Introduction

This chapter will offer a brief overview of the Inclusive Learning Initiative, explain the aim and purpose of the research and outline the structure of the report.

The Inclusive Learning Initiative

In 2009 the National University of Ireland Maynooth (now Maynooth University) and four other organisations - KARE, St. John of Gods Community Services, Stewarts Hospital and Camphill - established a Service Learning Partnership in order to identify ways of making higher education more inclusive for students with intellectual disabilities[1]. The Inclusive Learning Initiative (ILI) emerged as a result of the collaborative efforts of these five bodies.

In September 2011 five students with intellectual disabilities commenced their studies in Maynooth University under the auspices of the ILI (which is managed by staff from the Department of Adult and Community Education and the Higher Education Policy Unit both of which are both based on the Maynooth campus). The ILI appointed a Learning Facilitator to co-ordinate the day to day work of the project.

The five students who came into Maynooth University through the ILI are registered as occasional students. In keeping with the aim of the project to offer a 'fully inclusive' educational experience these students attend undergraduate lectures and seminars alongside full- time students and participate equally in the life of the university (Bracken 2012; Noonan 2012). To this end students are offered 'individualised support' on campus by the ILI, volunteers and other agencies.

---

[1] In Ireland and in the material disseminated by the ILI the phrase 'people/students with an intellectual disability' is the phrase which is most commonly used and will be employed in this report but a variety of terms are used in academic research and by state institutions and civil society organisations internationally. See Noonan (2012) for an overview and Barnes and Mercer (2010) for an analysis of how changing categories, terms and models relate to historical struggles over how disability is defined and understood.

The ILI has drawn on international experience and models of 'best practice' in inclusive education – most notably from Canada - in designing the project. The precise meaning of fully inclusive education based on individualised support will be elaborated upon in

the next chapter. For the time being I will simply sketch out some of the key features of the project. Bracken (2012: 8), who carried out research in 2012 on how Maynooth University staff see the ILI is worth quoting[2] at length here as she succinctly describes most of the main features of the initiative: the ILI sought to develop a programme in which:

- "Students would choose their own preferred course of study.
- Students would identify their own learning goals and set their own learning objectives.
- Students would enrol in standard college courses or programmes, attend lectures, tutorials and complete assignments and group work alongside the rest of the student body.
- Modifications and adaptations would be made by teaching staff to ensure students were included to the fullest extent possible.
- Support would be provided from a range of sources, including the ILI Learning Facilitator, on campus academic and social support structures, natural supports, student families, key workers and disability support agencies

  Flexible assessment procedures would be developed to reflect and reward each individual student's progress."

Bracken (2012: 8) also outlined how the following processes were established as a result of the work involved and development of the ILI:

- Students would be assessed and graded at the level of the work they present to the departments they are enrolled in.
- Students' development across three strands would be supported – Academic Learning, Social Learning and Personal Development.

At the time of this report, the students could choose from modules offered by seven academic departments. These were the Department of Adult and Community Education; the Department of Applied Social Studies; the Department of Anthropology;

_____
[2]All the bulleted points are quoted directly from Bracken's (2012) report, with some amendment in order of points and a job title for the purposes of consistency.

the Department of Design Innovation; the Department of Media Studies; the Department of Music and the Department of Early Irish.

All five students started their third year when this evaluation was being completed and completed their studies at Maynooth University in 2014.

The aims of the study and the rationale for the research

The ILI is a pilot project which is attempting to achieve something which Irish universities have not much experience or a great deal of expertise in doing. It is both innovative and experimental and for this reason ILI committee members have commissioned a number of studies to explore the value and efficacy of the initiative through consultation with Maynooth University and ILI staff, external stakeholders, ILI volunteers and the students.

This particular piece of research was undertaken to evaluate the initiative from the students' perspective. Given the remit and philosophical underpinnings of the ILI how the students see the project and Maynooth University is absolutely central to assessing whether the project has been successful and vital in working out how it might develop and improve in the future. Specifically the research set out to identify:

- Student experience of the transition to university life on campus at Maynooth University
- Specific challenges which the students may have encountered.
- Student experience of the supports available in the university.
- Student experience of the supportive educative relationship within their chosen department
- Student experience of the academic support, guidance and advocacy provided by the ILI Learning Facilitator.
- The perceived benefits of this initiative to the individual student in terms of personal, academic and social development

The structure of the report

The report consists of six chapters. Chapter two situates the ILI project historically and theoretically through a discussion of research and policy related to disability and education. In chapter three I will explain how the research was designed and conducted. The next two chapters are based on the empirical data and discuss the students' experience and what they say about being in Maynooth University. Chapter four discusses the challenges encountered by the students and the supports they drew upon in their first two years of college and chapter five will explore how the students discuss the overall benefits and limitations of participating in the initiative. The final chapter summarises the findings and discusses some of the implications of what the students said about Maynooth University and the ILI for thinking about the nature of learning and building a more inclusive higher education system.

Chapter Two
Contextualising the ILI: Disability, education and society

Introduction

Chapter two contextualises the study in relation to major themes within disability studies and with regard to recent trends in social and educational policy (in particular the commitment made by the state to improve access and equality in Irish higher education for people with disabilities).

The purpose of this is to provide sufficient background information to accurately interpret what the students had to say in the interviews and to place the project and the findings within a broader historical and theoretical horizon. However, due to the scale and focus of the research project, only a small amount of the relevant literature can be discussed and the aim here is to sketch out major lines of argument rather than offer a full and exhaustive account of disability studies and education.

Disability, education and society

Inclusive education is a relatively recent idea and has emerged in response to the systematic failure of the education system to make room for people with disabilities. From the inception of 'mass' education in Europe and America in the nineteenth and early twentieth century people with disabilities have been marginalised within, or entirely excluded from, schools and colleges (Barnes and Mercer 2010)[3]. As a rule the needs of students with disabilities have been ignored and people with disabilities were sent to segregated 'special' educational institutions or were even deemed entirely uneducable based on their putative incapacity to learn (Barnes and Mercer 2010; Kittay and Carlson 2010). Exclusion, segregation and stigmatisation in and through

---

[3] These are necessarily broad statements and it is worth bearing in mind that experiences of people with disabilities across the world are very diverse (Armstrong and Barton 1999; Barton and Armstrong 2008)

education has had grave and wide-ranging political, social and economic consequences (Baker *et al.* 2009; Barnes and Mercer 2010; Kittay and Carlson 2010)[4].

Understanding the full impact of social and educational exclusion and exploring how to overcome structural barriers has become a consistent and defining concern of disability scholars and activists (Armstrong and Barton 1999; Barnes 2007; Barnes and Mercer 2010; Barton and Armstrong 2008; Hurst 1996). Some of the most cogent and influential work on these issues has been developed using what has become known as the 'social model of disability'. This approach focuses attention on disabling barriers in society rather than on an individual's impairments (Barnes 2007; Barnes *et al.* 2002; Barton 2006; UPIAS and DA 1975). The articulation and development of this perspective which points to the socially constructed nature of disability led to a sea change (UPIAS and DA 1975). First, it challenged dominant discourses which treated disability as a personal tragedy or viewed people with disabilities solely through welfare or medical categories. Second, and just as importantly, it provided a theoretical and practical departure point for a generation of researchers and educators who maintained action *could* be taken to overcome disabling barriers[5].

There has also been a legislative turn in support of greater equality in society and education for people with disabilities and a move away in policy documents from treating disability in exclusively individualised and bio-medical terms (Barnes and Mercer 2010). Significantly, access to education for people with disabilities at all levels is now enshrined in the United Nation's Convention on the Rights of Persons with Disabilities (UN 2006)6. This commitment is shared by powerful transnational bodies such as UNESCO (2005) and the OECD (2003) and quite recently the EU has

---

[4] It should also be noted that some groups – for instance the deaf community – has made a case for the continuing value of specialised and separate educational institutions.

[5] The social model encompasses a broad range of approaches and there has been a lively debate within disability studies on how best to analyse the precise interplay between lived embodied experience and social and cultural barriers (Barnes and Mercer 2011; Barnes *et al.* 2002; Barton 2006).

[6] See especially Article 24 which deals specifically with education.

reaffirmed the need for "inclusive, quality education" in the EU's disability strategy document 2010-2020 (CEP 2010: 7)[7].

Access and inclusion in higher education

The commitment to inclusion at *all* levels of education is significant. Rapid growth in non-compulsory formal education – most prominently in third level institutions – over the past generation (Attewell and Newman 2010; Trow 1973) reflects the fact that college credentials now play a more central role in labour markets than ever before. Moving from an elite to a 'mass' system has also radically altered cultural expectations: today attending higher education is widely viewed as a 'normal', but nevertheless important, part of one's personal development[8]. Life chances and opportunities – however one might measure them – are increasingly bound up with access to higher education[9]. Consequently access has become a commonly employed litmus test for judging the level of social equality enjoyed by various social groups in many wealthy countries. Widening participation is also viewed as the best method of combating inequality and governments and transnational organisations frequently assert that tertiary education provides a solid foundation for meaningful social inclusion for people with disabilities "in every aspect of economic, social and political life" (OECD 2003:8).

So the complex effects of the expansion of tertiary education, alongside broader political and cultural shifts in the way disability is commonly understood, alongside legislative changes has made the exclusion of people with disabilities from third level education a far more visible and pressing issue. Although individual nation states have responded to this challenge with varying levels of effectiveness (OECD 2003) and there is clear evidence of enduring inequality there can be no doubt that that

_____

[7] For further information see Noonan (2012) and O' Brien *et al.* (2008) which foreground legislative change. O' Brien *et al.* (2008) attribute a good deal of influence to UNESCO.

[8] Of course empirical data indicates that access remains very unequal (Attewell and Newman 2010; Baker *et al.* 2009): the point here is that the idea of going to university has become more normative (for empirical data on this in an Irish context see Fleming and Finnegan 2011; Fleming *et al.* 2010).

[9] For example in relation to income, occupational choice, cultural capital, normative expectations, opportunities for personal development and access to valued cultural practices etc.

inclusive higher education is now firmly on the agenda in national and international policy and a defining issue in contemporary debates over access.

Scholarly interest in disability and access to education has grown apace in the past thirty years as well. As noted earlier this is not the place to explore this work in detail but a review of a portion of this work alongside the more general material on disability studies cited above is instructive (Adams and Brown 2006; Armstrong and Barton 1999; Baker *et al.* 2009; Barnes 2007; Barton and Armstrong 2008; Borland and James 1999; Field and Morgan-Klein 2014; Grantley 2000; Hughson *et al.* 2005; Hurst 1996, 1998; Kubiak and Espiner 2009; Lowe and McDonnell 2008; McDonnell 2000, 2003; O'Brien *et al.* 2008, 2009; Shevlin *et al.* 2004; Tinklin and Hall 1999). Going through this material revealed two things that I think are particularly germane to the present study. First of all, the increased scope and depth of disability studies has led to far greater general awareness of the complexity and diversity of experiences amongst people with disabilities. Simply put this research serves to underline the fact that students with disabilities cannot, and should not, be treated as a homogenous group. Second of all, although rhetoric and reality often remain at odds (McDonnell 2000) there *has* been a shift in many wealthy countries, however uneven and incomplete, to making higher education more inclusive in recent years. Improving physical access, making assistive technologies more readily available, raising awareness amongst staff and students about disabilities and even the call to rethink pedagogy are no longer 'unusual' demands but have become quite familiar ideas in many countries. Arguments about the desirability of more equal access for people with disabilities are widely accepted and the focus has moved on how best to implement, elaborate and extend the idea of inclusivity.

These interlinked developments – a heightened awareness of a diversity of experience and needs amongst people with disabilities and a richer and a more nuanced conception of inclusivity have led some commentators to conclude that a genuinely inclusive education system requires institutions that are open to people with all sorts of impairments including people with intellectual disabilities (Grantley 2000; Hughson *et al.* 2005; Kubiak and Espiner 2009; O'Brien *et al.* 2008, 2009; Shevlin *et al.* 2004).

A fully inclusive approach to higher education has been developed in a number of countries including in Canada, Australia, the USA, Finland and New Zealand (O'Brien *et al.* 2008)[10] [11]. One of the most influential, and ambitious, attempts to rethink third level education in this manner has been developed in the state of Alberta in Canada through the '*On Campus'* initiative (Hughson *et al*. 2005). This 'fully inclusive' model is premised on the idea that students with intellectual disabilities should be given the opportunity to participate in third level in every aspect of college life. In this vision

> students are viewed as inherently equal, not in their abilities, but in their personhood – in their desire to learn, to belong and to succeed. Students are viewed as learners who contribute to the classroom [and the] focus [is on] how to help each student succeed, how best to teach, not whether someone should be included or excluded on the basis of their disability.

(Hughson *et al.* 2005**:** 9)

In practical terms this means that students with intellectual disabilities should have the opportunity to engage in 'mainstream' modules and should be offered the necessary individualised supports to make full participation possible and that the onus is on the institution to work flexibly with the student to make this work.

This approach is therefore based on a critique of 'disabling barriers' linked to a substantive and multidimensional conception of access. From this perspective "in a university the essential meaning of access must be 'access to the curriculum'" in the broadest possible sense (Borland and James 1999:94). Inclusive education therefore goes beyond the provision of supports to individuals and entails a broad process of cultural, pedagogical and attitudinal change within institutions (Barnes 2007; Shevlin *et al*. 2004). One can trace the roots of this approach to earlier initiatives, primarily in Scandinavia, and an influential line of scholarship in disability studies (see Wolfensburger discussed in Barnes and Mercer 2010), which have been premised on the 'normalisation' of disability through integrative practices across society. It is this

---

[10] Thanks to John Kubiak for providing me with a general overview of international developments in this field. The information on New Zealand is not included in O'Brien *et al.* 2008) and was given by him.

[11] Recent developments in inclusive higher education in Ireland are outlined below.

'fully inclusive individualised' support model which underpins the work of the ILI (Bracken 2012; Noonan 2012).

Students with disabilities in Irish higher education

Before I move to the topic of inclusive higher education in Ireland I want to quickly sketch out a general picture of higher education policy in relation to people with disabilities. The expansion of higher education and a renewed emphasis in national and international educational policy on access and equality has reconfigured the landscape of third level education in Ireland over the past twenty years. The formalisation of the 'access agenda' in the mid 1990s led to a swathe of reports and new polices on access and equality (e.g. DES 1995a, 1995b, 2000, 2001; NOEAHE 2004, 2006, 2010; Skilbeck and O'Connell, 2000), the convening of an action group on access and eventually the establishment of a National Access Office. This policy shift is buttressed by social and educational legislation which includes a commitment to the principle of equality and new laws which are meant to safeguard and strengthen the rights of people with disabilities (notably the 2000 Equal Status Act, the 1998 Employment Act, the 1998 Education Act, the 1997 Universities Act, the 2005 Disability Act, and the 2006 Institute of Technology Act)[12] As part of this effort the Higher Education Authority (HEA) identified three key target groups they wished to support through access and widening participation policies and initiatives: mature students, working class students and students with disabilities (DES 2001).

The rationale for designating people with disabilities as an access group is clear: research has found higher levels of deprivation and evidence of persistent educational disadvantage - including very low levels of third level participation - amongst this section of Irish society (AHEAD 2006; DES 2001; Gannon and Nolan 2006; NDA 1996; Quin and Redmond 2003). Over the past fifteen years new entry and progression routes have been devised and a fund for students with disabilities was established to ameliorate this situation. Policies, procedures and charters related to

---

[12] For publication details and other relevant acts see Government of Ireland (1993, 1997, 1998a, 1998b, 1999, 2000, 2005, 2006).

access and inclusive education were also drawn up. Disability services also became more readily available through access offices (this has typically involved the provision of assistive technologies, learning support and accommodation with exams).

Progress in access has been monitored both by the HEA and the NGO AHEAD which collects data on students with disabilities. The participation rates of students with disabilities has risen from .65 per cent of the undergraduate student body in 1993/94 to 1.1 per cent in 1998/99 to 3.2 per cent in 2005/06 (AHEAD 2006: 3). In 2011/12 students with disabilities accounted for four per cent the total student population and five percent of the undergraduate student body (AHEAD 2012: 6). By far the largest group of students with disabilities are students with specific learning difficulty (such as dyslexia) which accounts for 57 per cent of students with disabilities (AHEAD 2012:11).

The high number of students with specific learning difficulties is a reminder that the access category 'students with disabilities' is heterogeneous. Despite the dramatic rise in overall participation[13] to a striking degree there has been very little focus in access offices, policy statements or from advocacy groups on the inclusion of students with intellectual disabilities in third level institutions. In fact, this appears to be largely unchartered territory in terms of widening access and is an issue which only beginning to be addressed in Irish tertiary education. Apart from the ILI an initiative was launched earlier this year in National University of Ireland Galway (NUIG)[14] and in 2006 Trinity College Dublin (TCD) approved a Certificate in Contemporary Living course developed by the National Institute for Intellectual Disability. This full-time course designed for students with intellectual disabilities takes place on the TCD campus and consists of work on a Certificate course and access to a number of

---

[13] It should be said though that the level of participation is still lower than the UK (Field and Morgan-Klein 2014; Shevlin *et al.* 2004) and researchers have identified numerous barriers and limitations in current provision (Lowe and McDonnell 2008).

[14] This was briefly discussed in the ILI focus group but I could not find much material describing this initiative except a press release (dated July 2013) launching the NUIG 'Going to college' project. There is no fully inclusive project in UCD but the efforts of the School of Justice should be mentioned here because of its advocacy programme and the sustained attention they have given to access and disability.

undergraduate modules (Kubiak and Espiner 2009; O'Brien *et al.* 2008, 2009; Shevlin *et al.* 2004)[15].

'Pushing the boundaries'[16]: Access and inclusive education at Maynooth University

Within the Irish university sector Maynooth University has taken the lead in promoting in access and the Department of Adult and Community Education has been particularly active in pursuing community outreach and widening participation. As a result Maynooth University has established a reputation, especially amongst mature students (Fleming *et al*. 2010), as taking the lead in widening access to Irish universities. In this sense although the ILI did not emerge from established access structures within Maynooth University it is part of a more general effort in the university to 'push the boundaries' of access and is in line with the goals on inclusive education set out in the Maynooth University strategic plan (Noonan 2012).

This is the first such initiative in Maynooth University. As I mentioned previously this type of access work is quite new in Ireland and consequently the ILI staff primarily drew their inspiration from the Alberta model in Canada discussed above (Hughson *et al.* 2005; see also Bracken 2012; Noonan 2012). In this regard the project in TCD has similar objectives and is informed by the same principles as the ILI programme. A caveat needs to be entered here though in making this comparison: the ILI puts more emphasis on individualised support for students and does not bring the ILI students regularly together as a group. In this regard the ILI's fully inclusive, individualised support model for undergraduate university courses is a new departure for Maynooth University and for Irish universities.

Conclusion

The chapter argued that the ILI is one small part of a more general effort to rethink how we understand disability and to identify and remove disabling barriers in society and education. Over the past generation the demand for equal treatment by disabled people has had an enormous impact on legislation, policy and scholarship. Providing access to all levels of education for people with disabilities is now an explicitly stated

---

[15] The TCD Certificate has been temporarily suspended and is currently under external review.
[16] This phrase is used by O'Brien *et al.* (2008).

goal in international policy and there are a number of innovative attempts across the world to make higher education more inclusive. While there has been a large rise in the participation levels of students with disabilities in Irish higher education, in large part due to the efforts of access offices, widening access for people with intellectual disabilities is only beginning to be considered in an Irish context. The ILI is one of a handful of pioneering initiatives which is making space for students with intellectual disabilities in universities in Ireland.

Chapter Three
Methodology

Introduction

The chapter will outline the design, conduct and analysis of the research. It will also discuss ethical considerations and give the reader a brief introduction to the people who took part in the study.

An overview of the research process

The research was conducted in the second half of 2013[17] in six phases. The initial phase involved meeting with ILI staff and designing the research through consultation and discussion. The second phase consisted of desk research primarily on policy and disability. As a researcher unfamiliar with the ILI it took some time to develop a proper grasp of how the project worked and I met with ILI staff members several times in order to build up a more detailed knowledge of the project. This proved necessary because although the ILI is a small-scale project it became clear that the initiative was quite layered and complex and that a good deal of non-codified and tacit knowledge is used in order for it to function.

In the third phase preliminary consultations were held with the students to explain the purpose of the research and to invite them to participate in the study if they wished. This was the beginning of a *process* to ensure fully informed consent. Subsequently, formal invitations to take part in the research were sent out to the ILI students. The invitation was accompanied with documents describing the aims of the study and what participation entailed**.** A schedule of interview questions was also circulated to the potential participants at this point.

All five students volunteered to take part in the study and the fourth phase of the research consisted of interviews with the participants held over two days. The fifth

---

[17] Most of the fieldwork including the main interviews took place between July and September before the students began their third year.

phase involved transcription and analysis of the data. Desk research on students' experience in other institutions in Ireland and further afield was also completed at this juncture. In the sixth and final phase a first draft of the report was written. After this a focus group with the ILI staff was held to enhance the researcher's understanding of some of the main themes, to clarify some details about the way the ILI operates and to begin a discussion of the findings. The provisional findings were then sent in easy to read format to all the students and was then discussed in detail with each participant in face to face meetings where they were asked for their approval before I submitted the final draft. A small number of amendments were made as a result of this consultation process with staff and students.

The participants

The students range in age between 24 and 33 years of age. Three of them are male and two are female and they all live within commuting distance of Maynooth University with their families and/or in supported housing. Two of the students were working before they enrolled in Maynooth University and one student continues to balance paid work with academic studies. The participants in the study are also involved in a wide range of activities outside of study and work and this includes amateur drama, competitive and recreational sport, journalism and voluntary and community work.

The five interviewees have followed quite varied educational paths before coming to college and went through both mainstream education and special educational institutions. All the participants were involved with organisations which work with people with intellectual disabilities and in part-time or full-time training before coming to Maynooth University immediately prior to enrolment. After entering college most of the students have maintained some sort of formal or informal connection with these agencies.

The students are currently enrolled in a range of Higher Education and Training Awards Council (HETAC) level eight courses in Arts, Humanities and Social Sciences. One of the five students took part in a Return to Learning course before embarking on degree level modules.

Ethics

From its inception the ILI intended to undertake research on the initiative and approval from the University Ethics Committee was sought and granted for the study prior to my involvement. In the preliminary stages of the research the ILI core staff and I met and discussed how I intended to approach the research. The main objective of this meeting was to identify how the research could be designed and conducted in a manner that adhered to the highest ethical standards and took full account of the specific needs of the interview cohort.

As I had limited experience in conducting research with people with disabilities and none with persons with intellectual disabilities a good deal of time was apportioned to discussion, consultation and reading about the ethics of research in the early phases of the study. This process was essential not least because the main method of data collection chosen for the study was semi-structured interviews which by their nature explore personal experience and can touch on sensitive issues and people's vulnerabilities (Merrill and West 2009; West 1996; Walmsley 1998). The ILI committee members' suggestions and advice – based on prior experience with research on the ILI and in disability organisations – was extremely helpful and directly influenced aspects of the research design.

During this period I agreed a broad plan of action with ILI committee members and that it was imperative to: 1) ensure fully informed consent: 2) devise an appropriate interview format that was ethical, open, supportive and genuinely dialogical: 3) guarantee confidentiality and anonymity to the participants: and later it was decided 4) that there should be a formal process of consultation with the participants about the findings included in the final report.

It became quickly apparent to me in the initial phases of the study that I needed to think through how to apply ethical guidelines and adapt what might be usefully termed an ethical 'sensibility' learnt in other research contexts to this particular project. Discussions with the ILI team, reading what scholars in disability studies had to say about the ethics of research (Aman and Hadden 2006; Hurst 1996; Iacono 2006; Iacono and Murray 2003; McVilly and Dalton 2006; Mercer 2002; Oliver 1997;

Walmsley 1998) as well as deepening my broader understanding of disability issues played a role in this[18]. I concluded that many of the main aspects of conducting qualitative research ethically in any given context – being clear about the use and benefits of the study, ensuring informed consent, considering the potential risks and vulnerabilities of participants, assessing how the power dynamics might shape the research and being reflexive about how voices are constructed and represented in the presentation of the findings – are the same but require an added layer of preparation when working with people with intellectual disabilities.

Informed consent is a cornerstone of ethical research and this is where extra groundwork was especially necessary (see Walmsley 1998; also the debate between Aman and Hadden 2006; Iacono 2006; McVilly and Dalton 2006). Ensuring informed consent requires clear communication about the purpose, process and objectives of the research and methods that allow one to ascertain that genuine assent has been given and that neither tacit nor overt forms of coercion have influenced a person's decision to participate. But ethics and informed consent cannot be approached *solely* as a matter of protecting a potentially vulnerable group against harm, risk and exploitation. Iacono (2006:173) contends that "the very notion of protection, however, invokes paternalistic protectionism, with a concomitant risk of non-inclusive and discriminatory decisions"[19, 20]. I decided that a researcher I had to be cognisant of risk and potential vulnerabilities but I also needed to be equally wary of falling into a form of paternalism which underestimates the capability of people with intellectual disabilities to participate in research on their own terms once the pertinent information is made available to them and has been communicated in an effective manner.

These reflections affected both how I went about securing informed consent and how the findings were generated and confirmed. On this basis I sought an extended process of consultation with the potential interviewees. The aims and the use of the research data was explained in a straightforward manner in face to face meetings and later in

---

[18] I drew on conversations about research and disability studies that I had with Roisin Hunt and Paul Fagan prior to the research.

[19] Hunt (2013) drew my attention to one of these articles and this particular quote and also discussed the issue of informed consent in relation to her research with me in great detail.

[20] Iacono is talking about how ethics committees approach research proposals but the point, I would maintain, applies more generally to researchers, educators and institutions working with people with intellectual disabilities.

writing. In the informal preliminary meetings – in which the researcher was introduced to the students by the ILI Learning Facilitator – it was stressed repeatedly that participation was not required or expected of any of the students. The students were told about the format of the interviews and the sort of issues that might be talked about if they took part. Following this a written schedule of questions was distributed (see Appendix III) along with an explanation of the use, conduct and ethics of research in an easy to read document (see Appendix II). A covering letter requested that the attached documents be discussed by the participants with support workers in advance of the interviews and that consent was then given in writing (see Appendix I). This was done to ensure that prior to participation the participants would have an opportunity to talk in some depth with a trusted person outside of the ILI about what would be entailed in volunteering to take part in the research. The purpose, conditions and use of the study were discussed again on the day of the interview and it was emphasised that the recording of the interview or the interview itself could be discontinued at any time.

The interview format was devised in order to ensure that the interviewees felt comfortable and that the interview was conducted in an ethical manner. Four people participated in each interview session: the interviewee, the primary researcher, a second interviewer - Jean Cassidy who works in KARE an organisation for people with intellectual disabilities - and a support person of the interviewee's choice. Advice was also sought from the ILI core team in advance of the interviews to identify any specific interests and needs individual interviewees might have. Topics which might touch unnecessarily on the participants' sensitivities or vulnerabilities were also discussed. The interviews were held in a room which was familiar to the students and effort was made to make the atmosphere as congenial and informal as possible. At the end of each interview it was reiterated that the participant could withdraw from the project if they so wished and the participant, co-interviewer and support worker were asked for feedback.

Verbal and written guarantees of confidentiality were also given at each meeting. The data was kept securely in a locked office. Due to the small size of the cohort ensuring

that the interview excerpts are fully anonymised presented real challenges [21]. For that reason the interviewees will be identified with a letter rather than a gender specific name and biographical information such as age, specific interests and details about modules has been stripped out of the transcript segments used in the report. For the same reason for a select number of quotes no identification will be given at all. Anonymisation has leached some of the biographical richness from the interview material and makes some of the writing a little clunky but this proved to be the only way to ensure confidentiality.

Research as a participatory process

A recursive, consultative approach was taken to the research in order to maximise the participation of the students in the process. The intention was to think *with* rather than *about* the students – and to ensure that the research accurately reflected their words and sentiments. I believe there are good ethical, methodological and political reasons for approaching the work in this manner. It has been repeatedly emphasised by activists and scholars within disability studies that how knowledge about people's with disabilities lives gets produced and used demands reflection and forethought (Hurst 1996; Mercer 2002; Oliver 1997). Not least because the representations and histories that people with intellectual disabilities have at their disposal "is not so much theirs as the history of others acting either on their behalf or against them" (Walmsley quoting Ryan 1998:128). Besides these macro concerns about how knowledge is produced I also believe that a participative and recursive approach can be used to arrive at more accurate descriptions of events and phenomena (Merrill and West 2009; Thomson 2006).

---

[21] During the early stages of the research it became obvious that the in-depth knowledge the ILI team members have of the students' life stories and even their patterns of speech means that even with these precautions it might be possible for ILI staff to guess who is being quoted in some segments. The only way to ensure that this did not happen would be to paraphrase the students rather than use quotes throughout the report but this would mean that how the students view college would be almost entirely lost as would any sense of their voices. This would largely defeat the purpose of the research. On this basis I made a decision that I would paraphrase only in the case that a student offered negative or controversial feedback on the ILI or made any sort of remarks which might in any way adversely affect the student inside or outside the ILI. No major dilemma emerged in reading through the transcripts but I have nonetheless been cautious in what I have attributed to any given student in the report.

In keeping with the individualised support model used by the ILI it was felt that a focus group or any other research process which brought the students together as a group for research purposes would not be commensurable with the principles of the ILI. This meant of course that group participation in discussing and approving the schedule of questions or later the provisional findings was not possible. However, the students were kept updated individually about the progress of the research.

In the final stages of the research an easy to read summary of the main findings was circulated (Appendix IV). Following this I arranged meetings which lasted between thirty minutes and an hour and twenty minutes with each participant and the ILI Learning Facilitator. I reiterated that the participants had the right to change or amend the report. The findings were discussed at length and approved by each participant. In doing this any issues of possible concern or contention were explored and care was also taken to elaborate on points where I felt the easy to read summary did not entirely capture the tone of the report or fully communicate how various findings were linked together within it[22]. Having an established relationship with the participants meant that these conversations were – to my mind - very rich, open and testing in the positive sense of this word. But this consultation was not without it challenges: by its nature research involves generalisation and accurately communicating how individual experiences are linked to overall findings within the report required a good deal of discussion. Overall, this helped me a great deal; it confirmed the key findings and clarified some matters. Following this I made some changes in wording and added some new footnotes and half a dozen sentences. Far more importantly it gave the students ownership over the process, generated good critical conversations and according to two students using a participatory process has made them feel more confident about dealing with interviews and research on their own terms.

---

[22] On a methodological level this process illustrated both the necessity and some of the limitations of easy to read summaries in participatory research conducted with students with intellectual disabilities.

Conducting interviews

The interviews used a pre-agreed set of questions but were approached in a way which allowed participants to discuss and elaborate upon what *they* felt was most important to them (Merrill and West 2009). On average the interviews were between 45 minutes and an hour long. The aim was to create interviewee-led discussions of student experience but the precise level of prompting and clarification from the interviewers varied in each of the interviews. I also made an effort to cross-check ideas and impressions by returning to topics from different angles in our conversations (Hunt 2012). Both before and after the interviews participants were asked for their feedback on the process. All interviews were digitally recorded and these recordings were then transcribed.

Supplementary data sources

The five semi-structured in-depth interviews with the ILI participants is the main data source. Field notes, some biographical artefacts offered by the students and portfolios of student work and an assignment submitted by one of the students were also collected during the study. Interviews recorded by ILI team members with four of the five students in 2012 were also consulted. The complexity of the day to day running of the ILI project and detailed information in the interviews – in which the students often used first names of people who the researcher did not know – meant that consultation with ILI staff to check on certain details was necessary on several occasions. A focus group with the ILI staff was also held in the final stages of the study. Notes were taken during this and during the presentation of the findings to the students. These were also used as sources of information.

The analysis of the data

So a good deal of contextual information was gathered through observation, informal interviews and a focus group with ILI staff and listening to the 2012 student interviews. This material helped to frame what the students were saying about their experience and was written up as notes. The key data set – the 2013 interviews - were intensively analysed and coded in stages. After the interviews memos were written up

on the interview process. The interviews were then listened to again and notes were added. Following transcription I employed some of the procedures developed by grounded theorists and used very simple descriptive codes to label content in sentences and segments (Charmaz 2006). The aim of doing this was to pay very close attention to what the interviewees said and remain alert to unforeseen themes in the data.

In the secondary analysis of the content recurrent themes were clustered together using more abstract codes. For obvious reasons many of these abstract codes reflected the type of preselected questions chosen for the interview schedule (for example transitions, supports, obstacles) but others were not anticipated and emerged from analysis (for example sources of motivation, family, identity, relationality and learning, lifecourse expectations, friendship and isolation etc.).

After this a narrative analysis of patterns in each individual interview was undertaken (West 1996). This involved paying attention to *how* the story was told (intensity of interest and modes of expression etc.) and the types of stories chosen as well (friendship stories, narratives of study etc.) as thinking about the overall thrust and tenor of the students' account. The findings of the content and narrative analysis were then tabulated on a spreadsheet. I then began to compare the findings across the cohort for commonalities and differences. The semi-structured nature of the interviews and the small size of the research cohort meant that this was quite a straightforward process and the key findings emerged organically. Nevertheless, in analysing the data and in writing the report I have actively sought to differentiate and problematise specific findings by seeking counterexamples within the material. I reread the transcripts several times after the report was written with the same intention.

One other issue emerged in the analysis of the transcripts. The interviewees used very different patterns of communication (for example in the frequency and use of anecdotes or choosing to speak in very personal terms or very generally etc.) This means that some of the transcripts are easier to use to illustrate the themes that emerged from coding. During the write up I have consciously endeavoured to retain within the report the full variety of experience and opinion I encountered through paraphrase as well as direct quotation.

As noted above small alterations and shifts in emphasis were completed in the wake of the focus group with the staff and feedback on the provisional findings given by the interviewees.

Conclusion

The research is a qualitative research project which is based on in-depth semi-structured interviews and also draws on field notes, artefacts and background data. Particular care was given to ensuring informed consent and that the research was conducted in a participatory manner. Findings have been generated through grounded and narrative analysis.

Chapter Four

The students' experience: transitions, supports and challenges

Introduction

This chapter details what the students said about arriving in college and managing the transition to third level along with the challenges faced and the supports used in successfully making it through the first two years in Maynooth University. The primary aim of the chapter is to give the reader a clear sense of how these things are viewed by students. At the end of the chapter building on the empirical findings on transition, supports and challenges I make a case on how best to interpret this information in relation to what the students said as a whole about their experiences in college.

Transitions and challenges

Choosing the course and getting accepted

All the students heard about the ILI through disability organisations and in several cases they were acquainted with some of the ILI staff before they applied. These prior engagements and networks are important to the students and appear to be part of the reason why they chose to come to Maynooth University. The process of applying for a place, including the candidate interviews were generally seen as straightforward and quite relaxed and the process was even described as *"informal"* by one of the interviewees.

All five of the participants recalled getting the news that they had been accepted with a good deal of pride and students reported that they were pleasantly *"shocked", "delighted"* and *"very happy"*. Significantly, the participants all chose to describe this as very important event for their families as well. One student said *"I got my letter to say that I was picked. [I was] really excited. My ma was over the moon about it. She was more excited than I was (laughs)".* Another student with a large extended family recalls: *"my mother [...] texted every single brother and sister"* and yet another said *"my mother thought it was a brilliant adventure".* One interviewee

described it as a significant event for both family and community and said: *"My family and my friends in my local community supported me, helped me and they were happy that I got a place in Maynooth"*.

Academic and social challenges

Despite the fact that all the students felt very positive about starting university the participants did nevertheless find the initial period in Maynooth University *"daunting"* and in some cases very challenging indeed. There were a variety of reasons why this was so and the interviewees chose to highlight two things in particular - the pressure of academic work and the trials and tribulations of making friends and establishing effective peer networks.

All five interviewees mentioned that they found some aspect of doing academic work in first year difficult. Given the fact that none of students had previously had the opportunity to study in such a demanding course this is perhaps unsurprising.

However, there was quite a high level diversity across the cohort in terms of just how difficult this transition was. For example one student F acknowledged *"I had some stress yeah"* but nevertheless said overall *"it was not bad and I'd say I loved it"*. Another J found it difficult saying s/he *"didn't think all the work would be this hard"* but at the same time felt *"woo hoo! I am student I can do what I want"*. On the other hand A recalls feeling *"panic"* and that *"the lecturers ...were going so fast"* and his/her *"head was melted"*. C said *"everything was real scary and real ... everything just kind of thrown on you"* and found some of the academic language impenetrable. D found *"the most challenging part was actually my assignments [...] the deadlines"* and talked about studying till as late as two in the morning to keep up. Over time all the students developed a set of strategies for successfully coping with academic demands (this will be discussed below).

According to the interviewees integrating with peers was a major part of settling into university life. Several of the students were very anxious about this at first. For example, A says s/he felt *"nervous and I was always at the top of the class so I was quite lonely"*. This particular student developed a support network quite quickly and

A says this made college seem doable. J shared similar concerns and said that building a good peer network was fundamental to finding her/his feet. Arriving in college J says suddenly *"you're speaking in front of thirty people that you never met before in your life telling then about yourself"* and s/he was worried: *"are they going to take them for who I am? And I was lucky they did"*. Again for J this also seems to have happened quite quickly.

However, some of the students' indicated that they encountered some difficulties in establishing peer networks and/or struggled with the new environment well beyond the initial settling in period[23]. In C's case this was particularly sharply felt and s/he found *"my first year was really, really tough"*. C explains s/he felt uncomfortable in a large institution:

> *because I came from such a small little area, [C then mentions two specific organisations which work with people with intellectual disabilities which C attended before Maynooth University]. Yeah, that was... my first impression […] the amount of people [in Maynooth University] there's like thousands of students there and I don't know how to approach people without kind of ... I kind of, I realised that I had that fear in me, I didn't realise it in [organisation X] and I didn't realise it in [organisation Y], I actually felt fine in there. And I don't know how to approach people without kind of ... I kind of, I realised that I had that fear in me […] I realised when I came here that I have that fear of approaching someone ...yeah and talking to them and trying to make a conversation with them because they are in groups, they kind of, they get into a group and then you realise and plus I was a part-time student so I wasn't in as much as other students were and they didn't know that […]*

C went on to discuss how this fear later fed into a sense of isolation and even turned into a bruising conflict with a *"clique"* of students and repeated that *"the whole year was very, very tough"* and even thought at one point *"I was actually going to leave. Yeah, I didn't feel comfortable"*. In retrospect C thinks some of this was due to his/her status as an occasional student and her/his classmates were thinking *"Oh why is C coming in so late and only one day a week or two days a week and we have to be in here every day' and they were just thinking that I was skipping classes"*.

It appears that this group of students were not aware of C's disability and the conflict was not based on prejudice. What is important is that C *did* associate this with

---

[23] See also Bracken (2012 especially p. 12)

previous negative experiences at school (some of which appear to be tied up with the experience of discrimination) and these events served to catalyse and intensify this interviewee's concerns and worries about her/his capability and suitability for university. These misunderstandings and peer conflicts played out over most of the first year but C managed to get over this with some help.

One other participant also explained how ordinary academic problems and everyday social challenges can quickly become deeply entangled with whether or not one should disclose the existence of a disability to peers and/or academic staff. In fact this student's first year experience was strongly coloured by whether s/he should tell others about having an intellectual disability. It was not as bruising as C's experience but it definitely affected this student's willingness to ask for support from people.

In summary, what the ILI students said illuminates just how crucial peer and friendship networks are for finding one's feet and successful participation in college. Moreover, the interviewees - as these excerpts above indicate - also tended to describe personal and academic development as very much *interlinked*. Finally, the data suggests how one is viewed, especially within peer networks, can be a particularly charged and complex issue for students with disabilities and this can make the issue of disclosure a cause of real concern and anxiety.

Supports

All the students have successfully continued with their studies despite the challenges detailed above and this is reflected in the fact that in telling their stories the interviewees did not chose to dwell for very long on the problems they had encountered. Generally the tone of the interviews was remarkably positive and all the students associated going to university with having a greater degree of freedom and choice in their lives.

This is reflected in the enthusiasm and depth with which the interviewees held forth on the topic of support. The participants discussed four main sources of support: 1) the core ILI team: 2) volunteers working directly with the ILI: 3) academic staff in Maynooth University: and 4) more informal support from peers, family, disability organisations,

community members and college friends. Each of these will be looked at in turn before I outline some broader implications of the findings on challenges and supports at the end of the chapter.

The ILI core team and the ILI Learning Facilitator

The participants were unanimously and immensely positive about the support they had received from the ILI staff. In fact the work of the ILI was repeatedly mentioned as a key factor in successfully making it through the two years. One student even felt:

> *I wouldn't have been able to come to college by myself, I know well I wouldn't, I would have been gone in the first year, probably the first month and I know that's terrible to not have that confidence in yourself but I know how I am and I know how I feel.*

While it would be a mistake to underestimate the importance of the students' own determination and efforts in succeeding at Maynooth University I think this quote captures just how strongly supported the students feel and just how important the ILI has been for them.

In particular, the efforts of the ILI Learning Facilitator who deals with the students on a day to day basis was singled out for extremely warm and effusive praise by all of the students. One interviewee said *"she is the main reason why I am here in college"* and another commented that she *"made a big, a huge difference"* and *"she is a great help"*. Both the transcripts and the fieldwork suggest that participants' regular contact with Learning Facilitator has powerfully shaped their impressions of the ILI and the university as a whole; as one participant put it *"there's a good few staff behind [name of ILI Learning Facilitator] [...] you have all that just [name of ILI Learning Facilitator] is [..] my main comfortable person that I always get in contact with"*.

When asked what precisely they valued about the work carried out by Learning Facilitator the students were eloquent and highlighted a wide variety of things. One interviewee gave a particularly detailed answer to this question saying she *"gives guidance to students, she gives support to students and the volunteers as well"* and then became more specific and discussed how she provided *"PowerPoint notes"* and helped

to *"break up assignments [and] goes over coursework then I go to my seminars to prepare for my lectures [..] and that helps me a lot - it gives me a boost before I [...] go into the lectures"*. This form of academic support was mentioned repeatedly as was the Learning Facilitator's role in liaising and negotiating over assessment formats and procedures with Maynooth University lecturers and tutors[24].

The students also said that they greatly appreciated the non-academic support offered by the ILI Learning Facilitator and for several of the students she is clearly viewed as a friend as well as a mentor. The interviewees underscored three things in particular: they were her understanding of them as people and their specific needs, her approachability and her flexibility. One student remarked she *"always there"* and *"someone to talk to"*. Another said *"she knows me and I know her"*. As might be expected the Learning Facilitator appears to have a particularly important role in times of stress. One interviewee talked about encountering problems and being under pressure but

> *I had [ILI Learning Facilitator] though to support me, she was very, very good to support me when I felt that way [..] she'd talk to me [...] like as like a friend like not just as ... just like a staff or something like that, she always just kind of was a friend to me, like she'd sit there and talk to me and listen to what I wanted to tell her and know how I feel and talk to me back*

It appeared that with each individual student the Learning Facilitator plays a slightly different role and that a good deal of the efficacy of the ILI is based on a capacity to listen and consult with the student in order to make contextual judgements about how to best deploy supports which gives individuals the help they require while also creating opportunities for autonomous decision making and personal choice.

The research data indicates that each student sought a different form of structured support which then evolved and changed over time. From the interviews it appears that several of the students work best within a highly predictable support structure: as one student said it was important that *"I have a routine that I stick with and [ILI Learning Facilitator] fits in my routine"*. The particular student later discussed facing new life dilemmas and linked this to a greater sense of autonomy but needed, and asked for, a

---

[24] Over the course of the research two students also granted me access to their planning portfolios which they compile and work through on an ongoing basis with the Learning Facilitator. This appears to be a crucial 'tool' for documenting, organising and reflecting on the students' learning and offers a window into these students' university experience.

highly structured support system to arrive at this point. For other students and one student in particular choosing *not* to avail of support and make their own mistakes was of equal importance. For one person being able to say *"No, I am alright when I need you I'll ask for your support"* was crucial on a number of levels not least that it helped, as s/he put it, to feel more responsible and *"mature"*.

The ILI and the ILI Learning Facilitator are greatly appreciated by the students and this seems to depend on a highly individualised, knowledgeable and attuned form of support work which has academic and social elements and which offers each individual the right – often delicately balanced – mixture of structured help and flexibility.

The ILI volunteers

One of the most innovative and successful features of the ILI project has been the development of a volunteer network of Maynooth University students who offer academic and social support to the students. These volunteers go through a formal induction before they work alongside the students and liaise with the ILI team thereafter. Four of the five students discussed the role of these volunteers as very important to them and for two of the five people interactions with the volunteers appeared to be a very central part of their college experience. D said *"where would we be without [ILI facilitator] and the volunteers?* [..] *they give help, they give guidance [...] they give time"* and F spoke with great affection and said the volunteer *"helps me and make me think"*.

It is noteworthy that when the participants talked about the volunteers they underscored many of the same things they mentioned in relation to the ILI staff. They said the volunteers *"break [academic work] down",* help with note-taking, revision and analysis of course material as well as completing assignments. Informal social interactions with the volunteers are also valued and the *"effort to get to know me and [the opportunity] to get to know"* others was seen as precious by D. Friendship with volunteers was explicitly mentioned by three of the students and C said that one of the volunteers had become *"a really good friend. [and ...] goes around to the colleges with me and hangs around with me as a friend and then helps me out with [named*

subject]". The volunteers also appear to have a role in helping the students build wider peer networks.

The work of the volunteers does require continuous oversight from the ILI though. For instance one of the students related a story of being paired with a volunteer who the student thought:

> *was a nice person but she just wasn't my type of person. [...] I didn't feel like I wanted to work with her and [ILI facilitator] said 'That's perfectly fine, you're allowed to say that you can't just go around and pretend everything is okay' [...] I just felt like I wanted someone my age that I could become a friend with them.*

Support from academic staff

The transcripts include frequent discussion of academic themes and topics but most of the students spoke very little about departments in a direct way. However, three students gave quite a lot of background detail about departments and support given by individual lecturers and tutors was mentioned frequently by all the students. On this basis I think support has been available and forthcoming in all the departments that are working with the ILI but the data is incomplete on this matter.

In terms of individual lecturers we have a fuller picture. Face to face meetings between academic staff, the students and the Learning Facilitator to discuss modules are very much appreciated. Support, the students said, is also offered through the provision of materials and notes in accessible formats in advance of lectures. In three of the five student accounts knowing the lecturer/tutor personally appeared important.
One of these three D explained

> *when I go to my lectures I always go to talk to my lecturers first and have a meeting with them, to see how I work. I always like to work slow and set out different plans for different lecturers. He was giving me PowerPoint notes and I got to know him before the lectures [...] they were just great to work with so that's why the lecturers are very important.*

C echoed this sentiment and said that once s/he *"knew the tutors"* they could feel *"comfortable in the class"* and had *"more confidence"*.

However, for J it was a willingness to be flexible about the format of assignments rather than approachability was the thing s/he needed most from lecturers and commented: *"it is useful because like it is kind of meeting people at their standards and letting them go on and do their own stuff"*.

Staff support is seen as essential by the students and involves three main characteristics: being approachable, demonstrating a willingness to meet with the student and adapt materials accordingly and showing flexibility with assessment and assignments.

The importance of non-institutional supports

Besides the ILI, the volunteers and academic staff the students also spoke about a drawing on a range of supports which were not initiated or sustained by the ILI or Maynooth University. The most important of these is peer support from other students – mainly classmates – and this featured prominently in two accounts. Again the academic and social tended to be closely intertwined in the student narratives and interviewees mentioned socialising with peers, both in person and on Facebook, as a way of having fun as well as sharing notes, revising material and getting through assignments. This aspect of college life was particularly important for one person and according to this student peer support was just as important as the support offered by the ILI. Talking enthusiastically and in detail about the bonds forged with other students this interviewee explained how s/he worked in collaboration with her/his classmates and spoke of one particular friend who *"always reads through an assignment with me and then […] puts a line under a mistake so I know myself what to fix".* It is perhaps significant that s/he is studying on a course which requires that students engage in a lot of groupwork and has a long and structured induction period.

All of the students discussed family support and this appeared to be a particularly important for one student who discussed this topic in detail[27]. D described his family as deeply embedded in the local community which had led D to take part in a wide

---

[27] In the final consultation positive and *negative a*spects of dealing with family expectations were discussed. For findings on the dynamic and sometimes challenging effect of inclusive education on families see Hughson *et al. (*2005) and O'Brien *et al.* (2008).

variety of local groups and this fed her/his sense of motivation and affirmed D's sense of agency in college. Participating in community activities was a clear source of motivation and support in one other student's narrative.

Interestingly all the students felt supported or at least very connected to people involved in disability organisations, such as KARE and the National Learning Network, where they had previously studied and worked. Having clear pathways and trusted pathfinders that connect the university to these community organisations appear to be an integral element to successfully developing a thick and integrated support network for the students.

Conclusion: a note on analysing supports and challenges

Identifying barriers and supports to successful participation is a well established, and often useful, way of framing what students say about their experience in educational institutions. The data is very clear that this group of students have encountered challenges, some of which are quite serious, yet all of the participants have persevered and flourished. In analysing why this is the case it is evident that each student drew on a range of supports most regularly on those offered by the ILI staff and volunteers.

However, it is important to maintain a sense of how differentiated this was across the cohort. The specific range and types of supports required by each person was distinct in each individual case and moreover the precise arrangement of these supports varied and changed over time. For example one student drew relatively little on institutional supports and heavily on peer networks in first year but this became more 'balanced' in second year. Others wanted more set patterns of support from which they have built independent routines. Integrating and developing different blends of support is largely the responsibility of the Learning Facilitator and takes a very specific set of skills, is time consuming and demands an institutional commitment to individualised support.

Furthermore, as was suggested in the brief discussion of non-institutional supports above it would be a mistake to frame the discussion *just* in terms of supports and challenges. As we shall see shortly aspirations, a desire for a greater sense of autonomy and choice, and the experience of *"doing something that I'm really enjoy"*

are also integral elements of these people's stories. The students' motivation – rooted in intellectual interests, social needs and future hopes – is its own source of resilience and agency.

For instance I noted earlier that all the students found the initial period in college very challenging. Over time the students adapted and devised for themselves a number of learning strategies which typically relied in varying degrees on personal determination, formal and peer support along with the use of technological aids. For example one student spoke of overcoming academic difficulties by listening repeatedly to audio recordings of lectures, watching videos on the subject and then returning to academic material with the ILI Learning Facilitator, friends and ILI volunteers. In one sense this is unremarkable and arguably all students rely on similar learning networks (Engestrom 2001; Lave and Wenger 1991; Wenger 1998). It is necessary to state this explicitly all the same as people with disabilities – as constructed through medical and welfare discourses- are far too often identified solely with lack and incapacity but the ILI relies on the efforts of the students themselves just as much as it depends on the availability and mode of provision of supports to function properly.

Chapter Five

The students' perspective: The value, benefits and limitations of the initiative

Introduction

Chapter four outlines how the students' view the benefits and drawbacks of being in college. Overall, the interviewees were certain of the value of the ILI and extremely upbeat about college but nonetheless within the accounts there is some evidence of existing, or potential, issues with the project. The benefits are explored in the first half of the chapter and in the second half a number of existing tensions and potential problems with the ILI are discussed.

The value of the project

In a report on Maynooth University's staff perception and experience of the ILI project Bracken (2012) noted that academic staff and the ILI team had witnessed remarkable academic progress and considerable personal and social development in the students. These sentiments were reiterated by ILI staff members on several occasions during the course of the present research project and what the students had to say about their experience validates and offers further insight into what this has precisely entailed[26].

The students themselves were unequivocal that studying in university had been beneficial for them and that attending Maynooth University had precipitated positive and significant changes in their lives. Again how this is exactly viewed and articulated varies a great deal from person to person and this idea was expressed with different levels of intensity. On the basis of the interview data it would seem that going to university is seen as very beneficial by two of the participants and extremely beneficial by three others.

---

[26] Listening to the two sets of student interviews (from 2012 and 2013) offered some indication of these changes as well.

In explaining why they think it has been so worthwhile, and in some cases even transformative, very similar reasons were offered across the cohort. These were 1) a gain in confidence, a new sense of capacity and increased autonomy 2) making new friends and acquaintances 3) being provided with access to opportunities and valued social practices which are now for many people a 'normal' part of the lifecourse (this was regularly linked by the interviewees to family experiences and expectations and sometimes to a conception of attaining full adulthood) and 4) the pleasure of tackling more intellectually challenging material and studying in a more self-directed manner and 5) that going to college will probably enhance their job prospects.

These reasons have been listed in the order of importance given to them by the students. However, this remark needs qualification: the data was not 'tidy' and the first four things were often described as interconnected and it would be inaccurate to suggest otherwise. Put simply the social and academic and the cognitive and the relational cannot be neatly carved up and separated from each other in the students' narratives. On this basis I think *what the students valued was a multidimensional and integrated social learning process*. The fifth benefit – enhanced employment prospects – is a little easier to demarcate as a stand-alone topic. All of the students discussed employment and two students[27] explored the specific occupational value of their award in some detail but no-one viewed future occupational choices as the overriding or sole benefit of attending college and for two of the interviewees this seemed a minor concern.

Two other benefits were also mentioned by some of the students who said that their successful participation in the project had wider social value and that: 1) the ILI was contributing to a progressive change in the way that disability is viewed in society 2) that they thought the ILI was doing something which could affect pedagogy and practices positively for all students on the campus.

[27] In both cases a number of their modules had a vocational element and their career plans predated ~~going to college and in all likelihood~~ directly informed what they chose to study.

In their own words: the benefits of the project

The next section presents the data in a way that will impart some sense of the how these various benefits are perceived by each of the students.

F said *"[I have] learned how to get to know people"* and has enjoyed the time spent with classmates, the ILI Learning Facilitator and one of the other ILI core team members as well as the volunteers. The social dimension of the college experience was very important indeed to this student. An enhanced sense of independence was linked by this student to having a greater range of choices and being treated as adult. F also spoke very enthusiastically about course content and was fascinated by several of the subjects s/he had covered. Studying was important to her/his family and was especially meaningful in terms of relating to, and being similar to, a much liked and admired sibling. Together these various aspects had fed a greater sense of autonomy and capacity and F is now *"more independent"*.

J said *"when I left school I knew I could learn more"* and *"I wanted to be the first in my family to go to college"*. S/he continued: *"it was always my dream"* and now *"I am doing something that I want to do"*. J loves some of the content and enjoys lectures and was a bit surprised how much s/he got absorbed by some of the course content. This student feels that having new responsibilities and even to make mistakes has been very beneficial. Consequently J feels *"I came out of myself"* and *"I got more mature"*. J's sense of self has also changed and sees now that "*people are relying on me"* and thinks s/he has become a *"role model"* for a younger family member. A good deal of the benefit of going to college stems from the opportunity to meet new people who s/he says *"I know I will be friends with after college"*. J now thinks *"education is getting yourself to know where you can go"*. Finally, as a result of the college experience this student is also more confident about his/her occupational prospects in the future.

A emphasised three things in particular – confidence, intellectual stimulation and opportunities for socialising – in her/his narrative. A recalls when s/he first did a class presentation *"my stomach was like jelly"* but is happy and proud to have overcome these fears and doing public presentations seems particularly meaningful to this

39

student. Certain aspects of the discipline A is studying really excite this student and s/he talked enthusiastically in the interview about a number of lecture topics. Some of this interest is rooted in family experiences and A mentioned several times that the course material has helped her/him to relate and understand family members in a different, and deeper, way. Overall, for A the whole experience over the past two years has affirmed that *"I do have ability"* and this student feels s/he now communicates more easily *"to different [sorts] of people"*.

D thinks going to college *"gives back confidence"* and thinks the course will be useful for him/her in the future. Like most, but not all, of the interviewees attending university has become norm in her/his immediate family over the past generation and s/he says *"they all [have] got degrees, diplomas and Masters and I haven't got that opportunity yet"*. As a consequence D believes *"college life is important for everyone [..] and hopefully in the end of my last year in college I will have a diploma"*. Besides which D has enjoyed *"getting to know people"* to *"meet for whatever, coffee or a chat"*. According to D the opportunity to learn something new, to follow a trajectory that is similar to other family members and to meet people have together had a profound impact on her/him: *"I have totally changed […] It is a new world"*. When asked about this D's response is worth quoting at length because it illustrates how s/he construes the benefits of attending college and how this relates to social inclusivity.

> *I've changed in so many ways because when I started in Maynooth I wasn't been excluded, I wanted to meet all of the volunteers, I wanted to work with [ILI Facilitator], I wanted to work with the lecturers to achieve my goals, to look forward to my life. It's all about moving forward ... it's leaving behind that. It's getting to know other people, like getting to know [D names two people] or anyone in the college and that's important [...] It's a totally different life for me.*

D also says that this has been a learning process for the college, the volunteers and society as whole about the nature of disability. It is necessary to *"see the person"* and *"work with me, understand how I work ....get to know the person"* and *"see I can [...] achieve my goals in college"*.

C is also enthusiastic when explaining the benefits of attending college: *"I'm studying something that I've loved since I was a kid and I've got my friends. I've built up my confidence"*. C then continues

> *I feel like I'm more confident, that I can just go and do something and I used to be afraid to go get a cup of tea by myself, would I look weird sitting there by myself, and now I just feel I can go walk in and get a cup of tea, sit down, take a book or something and read it. I just feel a lot [more] comfortable here.*

When the student was asked if family or friends have noticed a difference C responded *"Yes, my mam she even thinks I'm more mature, more grown up"*.

C also discussed the broader implications of participating in the ILI project.

> *A lot of people that I've been talking to and [...] I mostly tell them that the five students that are in here are actually doing something very good like ...we're taking on a role to show that we can make college a lot easier for students. That's what we're deciding what to do*

At this point C said something which has direct bearing on assessing some of the impact of a fully inclusive programme on the participants:

> *I thought actually we were going in here and we were going to be put into a class altogether and there was just going to be the five of us together and we weren't going to be able to get out and ... I thought it was going to be just like a course thing [..]a group course but I prefer that it wasn't anyway [...] because then I wouldn't have been able to go around and see the college and meet new people and I would have been stuck in with the same people over. You have more freedom and you're more treated like an adult and you're allowed to say what you're not allowed to say in school ...it's quite different in school [...] they give you more freedom*

This C has changed family expectations and that even parents of the ILI participants *"couldn't believe that their kids were in college doing this"*. This student says of his/her mother

> *when I was young and how I was very sick and all that stuff [...] she didn't even feel that that opportunity would ever come around and she couldn't believe it, sitting right front of her, that I was going to university [she] didn't think that opportunity would ever fall in front of me.*

While C think university is challenging she is now recommending others to come to Maynooth University through the ILI.

41

In summary, all five of the students are remarkably positive about being in college and see it as personally and socially beneficial and describe it as a multilayered process of development and inclusion.

Tensions, limitations and concerns for the future

Part of the purpose of engaging a researcher who had no previous connection with the ILI was to ensure the participants could voice issues or concerns that they perhaps would not want to air with members of the ILI team. Before and during the interviews participants were encouraged to articulate any criticisms of the ILI they might have but very little negative feedback was given over the course of the research. In conversation with the students and through data analysis I actively tried to find counter examples or fissures in the bigger story but did not find much evidence of problems in the ILI. Despite being overwhelmingly positive the interviewees did in the various discussions identify issues, problems and tensions which although they tended to minimise are worth highlighting here for the purpose of discussion and reflection.

Given the importance ascribed to friendship and building peer networks by the participants it should be reiterated that this happened unevenly and in some cases quite slowly. Furthermore, a good deal of the peer support is a direct product of the efforts of the ILI. The interviewees reported misunderstandings with other students over intentions and behaviour, gaps in age, experience and gender and their exact status on courses. These conflicts were also was noted by a staff member in an interview conducted for Bracken's (2012) report on staff perceptions of the ILI.

Obviously integration does not happen automatically and during one interview one student even ruefully remarked that even now *"I am quiet, not all the time. I don't want to be either"*. In the interviews and during the consultation on findings one student discussed the impact of being looked at it in a demeaning way and another reported witnessing very prejudiced behaviour towards another student with a disability. Generally the students are not isolated and open prejudice about disability appears to be rare but I think underlying some of the students' comments is a lived experience and/or an awareness of the effects of exclusion. It is perhaps telling that

ILI students did not speak about student societies and clubs and only one of the students discussed having had a lot of opportunities for socialising with other Maynooth University students off-campus. In other words the networks of interaction could be usefully widened. Discrimination can be deeply corrosive and as a great deal rests on creating a *generally inclusive teaching and learning culture* these things cannot be overlooked.

Only one student offered any criticism of a Maynooth University staff member and this was very mild[30]. The main issues here were a lack of time, concern and knowledge of the student as a person on the part of the academic. This was not seen as serious by this student and as the exception rather than the rule and was used to illustrate the difference between this one particular lecturer and the student's general experience of dealing with staff.

All the students have built very strong relationships with the ILI staff and in particular the ILI Learning Facilitator. Both participant observation and the interviewees' accounts suggest that this work is vital to the functioning and success of the ILI. However, the interviewees indicated that the role of the ILI Facilitator seemed *"busy"*. This can be placed in the context of the initiative's development at this time. The original role of the ILI Facilitator was intended to be supported by existing institutional supports, as in the Alberta model (Hughson et al., 2005), but due to the ILI students' registration status as occasional students, ILI students did not qualify for the Fund for Students with Disabilities (FSD) and therefore could not receive the full suite of supports offered by Maynooth University Access Programme (MAP) and Disability Support Service. However, students did avail of both individualised and group technology and assistive technology support, software and training offered by MAP. Further learning supports were required and after internal consultation, the ILI Facilitator decided to support the five students concurrently during the initial period (including in-class notetaking, educational and tuition support, personal assistance, technology usage support, assignment support, class preparation and review support, depending on the individual).

In conjunction with this, the ILI facilitator and team worked with departments and support services across the university to put supports in place such as more diverse and

inclusive teaching, learning and assessment methods, more tailored library support training, technology support, mentorship to support student engagement and supporting both students and staff with these developments. They were cognisant that natural supports of students going through the same experience of being in college were valuable supports. They consulted with students, and the student engagement officer in MU and other colleges, and recruited MU students as learning partners to assist the ILI students on their college journey in different capacities.

The process and nature of support provided was facilitated through individualized planning and guided by each student. This was an unique response to the institutional needs for support at the time and sustainable institutionally-based supports is something to consider for future inclusive initiatives. Drawing on the Alberta framework, the facilitator's job is to support students to use existing support structures, but also to help develop those support structures/ pathways to support both students and staff.

These connections and supports brought their own concerns for the ILI students. Fears about being paired with a volunteer that students did not identify with, or feel comfortable working with, were brought up but again when this did occur it was dealt with promptly and effectively. Some concern could also be detected in students' descriptions of well liked volunteers *'moving on'* and although this is inevitable given the nature of volunteering this is a possible source of real difficulty.

———————————————

There were also some low level anxiety amongst the interviewees about the choices and pathways that would be available to them after they finish their studies in Maynooth University but there was a great deal of confidence that the ILI team would help them negotiate these choices in the future. Undoubtedly, what happens next to the students will have a good deal of bearing of the long term efficacy of the initiative if the ILI moves beyond the pilot stage.

Although there are relatively few ILI collective events during each academic year a sense of solidarity and friendship between the five students was common. For instance one student voiced his/her desire for further opportunities to *"come together to celebrate all the students have achieved in life"*. A public seminar earlier in the year was discussed with great excitement as an affirming example of what ILI is doing by most of the students. Inevitably a project like the ILI has its own gravitational pull and informs what all the students think and feel about being in university as a whole. Nevertheless, as might have been discerned from the excerpts used in the previous part of this chapter, individual students position themselves in very different ways in relation to the ILI and differ on how they exactly view its role. So some students are excited by the fact that it might have a broader significance (*"it would be a brilliant idea to make it bigger and broader"*) and others relate to it on mainly individual terms. Of course this is to be expected but there is a potential tension here in the fact that some of the students see the ILI *itself* as part of a shared identity and others do not. This sort of identification is necessarily bound up expectations of one sort or another which may not be possible to satisfy and handling this with a different or larger cohort might prove tricky.

On a related matter some ambivalence was expressed about the low level visibility of the project on campus. One student explained:

> *the [ILI] doesn't want to pinpoint them [...] like we're normal students walking around the college doing what other college students doing [...] not to make such a deal out of it you know [...] that we should all be treated the same as every student around there. I feel even every student in the college should be on this [...]It's too hidden because we're not even allowed to go around and ... we are allowed but they'd rather we didn't make too much ... all the students, most of the students around here actually know and most of the tutors know but they'd rather we didn't go around saying it too much.*

I think this quote captures some of the complexity of making individualised, fully inclusive education a reality. The ILI is meant to be an 'adjunct' support structure which facilitates the full college experience but its success means some students identify very strongly with it and feel *"it remains too hidden"*.

Students' worries about disclosure and a certain amount of ambivalence about the relationship between the ILI to the university as a whole are to be expected (see also Bracken 2012). However, I think this is part of a bigger story: Field and Morgan Klein (2014) have noted amongst students with disabilities there is often a considerable, and wholly understandable, sensitivity about how one is viewed and categorised by institutions. In this sense it is obvious that the work of the ILI and these individual students' experience cannot be isolated from the more general question of how people with disabilities are viewed, and often misrecognised by others, within higher education and society.

What the data suggests is that small changes can make a big difference but that initiatives like the ILI also pose larger questions about how *generally inclusive* the university is and that students on the ILI still have to struggle to find a way of dealing with the dominant categories and discourses which continue to define how disability is viewed more generally.

Conclusion

The data indicates that the students view the ILI very positively and believe that it has been beneficial in numerous ways including in terms of building confidence, providing opportunities for social interaction and fulfilling personal ambitions and satisfying normative expectations.

There was very little negative feedback offered by the students but their remarks and insights were used to highlight concerns and potential issues such as difficulties in peer integration, reliance on a highly committed support worker and the status of the ILI within Maynooth University and the effect broader discourses and modes of categorisation have on student experience.

Chapter Six
Summary of findings, discussion and recommendations

Summary of key findings

The fieldwork and interviews demonstrate that according to the students the ILI is a success. From the students' perspective coming to Maynooth University has resulted in them feeling more autonomous and given them a greater sense of confidence. The students enjoyed learning new things and having the same opportunities as their peers and family members. Some students believe that going to college will improve their chances of getting interesting work. In discussing both the personal and academic benefits of attending Maynooth University the students put a particular premium on meeting new people and the data strongly indicates that dense networks of support and interaction is at the heart of what students deem worthwhile about college. On this basis I think the students' experience within Maynooth University is most accurately described as an inclusive, multidimensional social learning process.

The students have encountered challenges namely 1) managing the transition into college, 2) devising effective strategies for dealing with academic demands and 3) developing 'thick' peer networks. They discussed some communication problems with classmates, not feeling comfortable with assigned volunteers, worried about valued mentors moving on and the difficulties associated with (non)disclosure of a disability. Some interviewees also faced or witnessed prejudiced behaviour from other members of the student body on a few occasions.

The students were immensely positive about the role of the ILI. The interviews and the fieldwork suggest that the ILI team and the ILI volunteers provide effective social and academic support in an unobtrusive and facilitative manner which responds to each of the five students' individual needs. All of the students discussed this at length and were particularly effusive in their praise for the ILI Learning Facilitator. While the students were unanimously positive in their evaluation of the ILI the research

indicates that there are very different modes of identification with the project amongst the five individuals.

Obviously the work of the ILI relies on academic staff being approachable, supportive and flexible in their approach to pedagogy and assessment. The students reported very few problems with the university and were enthusiastic about their interactions with Maynooth University staff. It seems that the enthusiasm and determination of the students has been responded to by tutors and lecturers with consideration and openness.

One of the most important functions of the ILI has been in forging networks involving staff, students and volunteers which in time develop into an ecosystem of supports and interaction. In fact a good deal of the success of the project can be ascribed to the ILI's capacity to do this sort of work by effectively communicating between different parts of the university and working with diverse academic cultures while keeping the individual needs of students firmly in mind. Establishing and maintaining support networks has required a good deal of collaborative effort from the ILI team as a whole and a high level of commitment and grounded knowledge from the Learning Facilitator. It is noteworthy that although 'unanticipated' and 'organic' supports have emerged over time formally ILI sponsored networks have been crucial.

Overall, the research suggests that highly individualised, flexible support works very well for students who are determined and committed. It demonstrates how access to higher education can be widened to include students with intellectual disabilities. The very high level of student satisfaction suggests that in doing this work the ILI is making a significant contribution to the store of knowledge and practices which could make Irish universities more inclusive in the future. This then prompts the question how can this be sustained and/or replicated.

Discussion

Comparing the ILI findings with other studies of student experience[28]

The first thing that should be said is that many of findings are very similar to what has been discovered through interviews with a wide variety of student cohorts in Maynooth University and other third level institutions. For example intertwined concerns about academic ability and peer acceptance are commonplace amongst all sorts of 'non-traditional' students when they first arrive in third level institutions (see Fleming and Finnegan 2011; Fleming *et al*. 2010). A number of other findings discussed above – such as the strong emphasis on the relational dimensions of education (especially in terms of peer support) [29]and the role of personal resilience and determination in making it through college - has surfaced in interviews with students across Europe (Finnegan *et al.* 2014). Similarly, the role higher education can play in building confidence has been a recurrent theme in all these research projects.

Despite these commonalities across a variety of student groups it is nevertheless enlightening to compare the findings with research which has documented students with disabilities[30] experience in other third level institutions (Borland and James 1999; Goode 2007; Grantley 2000; Holloway 2001; Hughson *et al.* 2005; Hurst 1996, 1998; Kubiak and Espiner 2009; Lowe and McDonnell 2008; Field and Morgan-Klein 2014; Shevlin *et al*. 2004; Riddell 1998)[31].

A regular theme in these studies is the importance given by students to how disclosure of a disability is handled (Borland and James 1999; Field and Morgan-Klein 2014; Shevlin *et al*. 2004; Riddell 1998). There are three aspects to this: timing, who the information is disclosed to (peers, support workers, academic staff etc.), and the extent to which the student has control over this process (Goode, 2007; Field and

---

[28] Adapting a version of grounded theory for analysis (Charmaz 2006) I decided to examine findings on student experience in the penultimate phase of the research rather than prior to the fieldwork to avoid unduly influencing the coding process.
[29] See also Keane (2009).
[30] The literature mentioned here is with students with a wide range of disabilities.
[31] As an aside in the 1990s Alan Hurst (1996) noted the dearth of research exploring the lived experience of students with disabilities but while this topic still remains under-researched there has been a steady growth of studies examining this in recent years.

Morgan-Klein 2014). This was also a significant topic in the present study (see also Bracken 2012) and especially in first year this is a particularly charged issue (see Goode 2007). Despite this the students who discussed this found a way of satisfactorily dealing with this and felt they were supported by the ILI and highly valued the fact that they were given control over disclosure. This was discussed at length in the student feedback sessions as well; interestingly disclosure to academic staff was seen as relatively unproblematic (based I think on how the ILI has managed this over the past two years) but worries about how disclosure might affect peer acceptance were reiterated. One student's solution to this was to slowly feed information to peers in a piecemeal fashion rather than deal with it emphatically and directly. There is of course no 'right' way of approaching this but giving the student control over the decision whilst offering advice and support as the ILI has done seems to offer the best strategy for making this easier for students.

The other issue that frequently surfaced in this research and which has a direct bearing on this study is that received ideas about disability strongly influence the way individual staff members behave and institutions function (Borland and James 1999; Field and Morgan-Klein 2014). Research with students with disabilities in the UK (Holloway 2001; Riddell 1998; Tinklin and Hall 1999) and Ireland (Lowe and McDonnell 2008) has discovered very marked disparities between staff and disabled students' conceptions of disability and conflicting ideas of what inclusive education requires. These studies strongly suggest that there is an uneven awareness amongst academic staff of the needs of disabled students and that highly medicalised or deficit notions of disability are still quite prevalent.

Bracken's (2012) study found high levels of goodwill among Maynooth University staff towards the ILI (even if there was some confusion about it and some remain unconvinced about the value of the project). This is reflected in the students' accounts and they reported very few problems with either the staff or the institution. However, given the findings of the research cited above it would be unwise to think that the potential for conflict or misunderstanding between staff and students with disabilities does not exist or that misconceptions about disability or discriminatory practices are no longer an issue. With this broader picture in mind I think it is possible to surmise two interconnected things from the positive reports of the students. First, it appears the

fully inclusive approach based on individualised support and the ILI's scaffolding of social and academic networks lessens the likelihood of students encountering these sorts of problems. Second, the ILI team's work on the ground communicating and liaising between staff and students has in all likelihood stimulated *institutional learning* on the nature and practicalities of fostering a more inclusive learning environment in higher education.

Institutional cultures are also, to varying degrees, shaped by students. Tinklin and Hall (1999) discovered a lack of awareness amongst non-disabled students and the interviews and the feedback sessions with the ILI cohort suggests this is an issue, albeit not a major one, in Maynooth University. With this in mind it could also be speculated that one of the most important strands of this institutional learning is occurring between classmates through informal interaction and through the work of the volunteers.

Comparison of findings from research with students with intellectual disabilities enrolled in inclusive programmes in Ireland (Trinity College Dublin), Australia and Canada add weight to the contention that such programmes might play a role in minimising the likelihood of students encountering discrimination and misunderstanding (Grantley 2000; Hughson *et al.* 2005; Kubiak and Espiner 2009; Shevlin *et al.* 2004; O'Brien *et al.* 2008, 2009). In all these programmes there appears to be a high level of student satisfaction. Furthermore, if one looks at these studies undertaken within 'sister' programmes more closely and what precisely students chose to foreground as important and why they are satisfied one discovers a familiar set of themes. In each case one of the most commonly reported strengths of inclusive programmes is that it bolsters students' social and academic confidence and leads to an enhanced sense of self (Grantley 2000; Hughson *et al.* 2005; Kubiak and Espiner 2009; O'Brien *et al.* 2008). Participants in these various programmes place enormous value on social interaction and building new relationships (Grantley 2000; Hughson *et al.* 2005; O'Brien *et al.* 2008). There are other similarities as well: in Canada the facilitator's work was also discussed as a key factor in ensuring success and building relationships and academic work were also seen as major challenges (Hughson *et al.* 2005).

A couple of other pertinent things can be learnt from comparing the data on fully inclusive education across institutions and national contexts. The ILI is still at a very early stage and more established initiatives are better placed to assess the broader effects and the full biographical, occupational and social significance of inclusive education. In TCD they have had the opportunity to compare findings from family, facilitators and students and one theme surfaced which was only suggested in the present study – that inclusive learning "due to an expanding range of experiences" alters family dynamics (O'Brien *et al.* 2008:73). This is hinted at in the Irish data but requires further research to be properly fleshed out and fully understood.

Canadian researchers (Hughson *et al.* 2005) are in the unusual position of being able to assess the impact of over twenty five years of such initiatives. They also found that fully inclusive educational programmes can positively affect families. Similarly, the finding that inclusive education enhances occupational choice (Hughson *et al.* 2005) appears plausible but it is too soon to say if this will also prove to be the case for the ILI.

The one major difference I can pinpoint between the findings of the present study and studies on these other inclusive projects is that disclosure was not highlighted as frequently by students in these other projects. Why this is the case is not clear but it may reflect organisational differences within the various initiatives, differences in student cohorts and/or very distinct socio-cultural contexts.

Some reflections on learning on the ILI

The ILI is a small-scale pilot project. It does not have extensive funding and it is important to bear in mind that students who access college through the ILI are registered as occasional students and therefore could not avail of the full range supports from the Access office. Nevertheless, all five students have flourished and gained a great deal from studying at Maynooth University. The interviews with the students indicate that despite the small size and experimental and modestly resourced nature of the ILI project Maynooth University currently finds itself at the forefront of exploring how inclusive higher education might be developed in Ireland for students with intellectual disabilities.

Obviously within a short research report based on a limited amount of data the pedagogical and social significance of the ILI cannot be discussed in great depth but it would be remiss not to outline, however briefly, some of the broader implications of what the students had to say about learning and pedagogy in light of the fact that it appears to have been quite effective.

Three interrelated things stand out very clearly in the student interviews – the centrality of relationality to every aspect of student experience and learning, the importance of individualised support and the collaborative and collective nature of social, cognitive and personal development.

The interviews revealed a densely textured world of relationality: care is at the very heart of what the students and staff deem important about the ILI. Right through the narratives - in the students' description of their decision to enrol, in discussing the benefits and difficulties of the initiative and in the warp and the weave of how they talked about everyday life on campus - are human relationships of care and concern. In this respect the empirical data supports the feminist argument that care and relationality should be far more central to theories of learning and education (Gilligan 1982; Kittay 1999; Lynch *et al.* 2009; Noddings 2003)[32].

A core principle of the ILI is that individualised support is crucial for inclusive education (see also Grantley 2000; Hughson *et al.* 2005). This informs the team's close attention to the specific needs and learning styles of participants in day to day work (and this orientation is very clearly reflected in the Person Centred Planning documents used by the ILI). This is an idea which is commonly expressed in education and psychology (Dewey 1916, 1938; Gardner 1999; Knowles 1970; Rogers 1983) but less commonly honoured in educational practice and the ILI offers an example of some of the strengths of this approach. The value of individualised support may be a well-established and familiar argument but the data reaffirms this and I think recognising this still has profound, and largely unexplored, implications for how we might approach education at all levels and how supports might be deployed for other groups of students in higher education.

---

[32] Care as a topic for serious consideration in philosophy, education and society was largely overlooked before feminism.

The student narratives also indicate the importance of the profoundly collaborative nature of learning. Learning on the ILI very clearly occurs within collective learning networks made up of peers, staff, mentors texts and other artefacts. With this in view I would make the argument that dominant models of learning and education remain far too obsessed with what an *individual* has *already* achieved at a given point. Against this it has been persuasively argued that we should be more concerned with how we can usefully enhance human capabilities through *collaboration* between novices and experts within networks (Engestrom 2001; Lave and Wenger 1991; Wenger 1998). Perhaps the most appropriate metaphor for understanding the distinction being made here is that effective pedagogy and learning requires scaffolding to create what Vygotsky (1978:84-91) called dynamic 'zones of proximal development' to explore what students c*an* achieve with the help of others. Over time, Vygotsky and these other theorists believe, that such future orientated collaborative forms of activity allow individuals to develop higher levels of independent capacity.

In this regard the data from the ILI is hardly definitive but it is nevertheless very suggestive. Arguably what the ILI is doing is creating zones of development based on academic activity as well as opportunities for friendship and interaction linked to a support structure that fosters caring relationships which are developmentally and educationally generative.

Overall the students' interviews offer an interesting insight into inclusive learning and pedagogy. I think the data indicates that disentangling the cognitive and the social dimensions of education and the individual and collective aspects of the learning process is fruitless. Mapping and fully understanding the effective meshing of these processes falls outside of the remit of the present study but I think further investigation and theorisation could be useful.

Education, the modern university and cultural change

It has been argued (O'Brien *et al.* 2009: 285) that

> Being included within a university setting opens up a whole new way of being for students who have previously experienced marginalisation. Such inclusion is a cogent way to promote ability

This study suggests these claims are credible and that small scale interventions can significantly change the expectations of students. Besides which I have already argued that it appears that the ILI is stimulating a form of institutional learning as well as individual student learning. I think it is therefore accurate to characterise the ILI's work as having an effect on multiple levels which involves students and staff in an attempt to imagine how a fully inclusive university might work.

Field and Morgan-Klein (2014) argue that over time such work can also have a profound effect on how disability is viewed beyond educational institutions. The students mentioned shifting expectations quite frequently in the interviews. For example F said *"staff [in my previous workplace] were in shock"* when this student began university and A mentioned that co-workers *"can't believe it".* In this sense the argument that inclusive initiatives have the potential to alter how we view disability more generally appears credible (Barnes 2007; Hughson *et al.* 2005).

In this regard the work of the ILI can be framed as part of a more general cultural shift in our understanding of the capacities of people with disabilities. Historically, dominant social expectations of people with intellectual disabilities have been very limited and profoundly limiting (Kittay and Carlson 2010). Philosophers who have paid attention to this shift argue that this should not be seen as a minor or 'marginal' change and has, and should, deeply affect how we conceive of society and education (Kittay 1999; Kittay and Carlson 2010; MacIntyre 1999; see also Apple 2013; Barnes 2007). Rethinking how we frame and discuss disability allows us to explore issues which affect all of us and are at the heart of everyday life – learning, interdependency and care – in a more nuanced and accurate manner. From this perspective the work of the ILI is valuable not only because it enhances individual students' lives and helps to widen access to university – which are very worthwhile things in their own right – but also because it also part of a much broader, and necessary, process of reflection on the conditions for human flourishing.

Bibliography

Adams, M. and Brown, S. (2006) *Towards an inclusive higher education: devising curricula for disabled students.* Milton Park, Oxon; New York: Routledge.

AHEAD (Association for Higher Education Access and Disability) (2006) *Students with disabilities in higher education: survey on provision for students with disabilities in higher education for the academic year 2005/06.* Dublin: AHEAD.

AHEAD (2012) *Students with disabilities in higher education: survey on provision for students with disabilities in higher education for the academic year 2011/12.* Dublin: AHEAD.

Aman, M. and Handen, B. (2006) 'Reactions to Iacono', *Journal of Intellectual & Developmental Disability*, 31(3): 180–182

Apple, M. (2013) *Can education change society?* Milton Park, Oxon; New York: Routledge.

Armstrong, F. and Barton, L. (eds) (1999) *Disability, human rights and education: cross cultural perspectives.* Buckingham; Philadelphia: Open University Press.

Attewell, P. A. and Newman, K. S. (eds) (2010) *Growing gaps educational inequality around the world.* New York; Oxford: Oxford University Press.

Baker, J., Lynch, K., Cantillon, S. and Walsh, J. (2009). *Equality: from theory to action* (2nd edn). Basingstoke: Palgrave Macmillan.

Barnes, C. (2007) 'Disability, higher education and the inclusive Society', *The British Journal of Sociology of Education, 28*(1): 135 – 145.

Barnes, C. and Mercer, G. (2010) *Exploring disability* (2nd edn). Cambridge :Polity.

Barnes, C., Oliver, M. and Barton, L. (eds) (2002) *Disability studies today,* Cambridge; Oxford: Polity in association with Blackwell.

Barton, L. (ed.) (2006) *Overcoming disabling barriers: 18 years of Disability and society.* London: Routledge.

Barton, L. and Armstrong, F. (eds) (2008) *Policy, experience and change: cross cultural reflections on inclusive education* No place: Springer.

Borland, J. and James, S. (1999) 'The learning experience of students with disabilities in higher education. A case study of a UK university', *Disability and Society,* 14(10): 85–101.

Bracken, M. (2012) *An evaluation of the Inclusive Learning Initiative: departmental level*. Unpublished research report: Maynooth University.

Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London: SAGE.

CEP (Commision to the European Parliament) *EU's European disability strategy 2010-2020.* Brussels: CEP
Available on-line:
<http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOTcommitment> Accessed 19/9/2013

DES (Department of Education and Science/Skills) (1995a) *Charting our Educational Future* Dublin: DES.

DES (1995b) *Report of the steering group on the future of higher education* Dublin: DES.

DES (2000) *Learning for life: white paper on adult education*. Dublin: The Stationery Office.

DES (2001) *Report on action group for access to higher education*. Dublin: The Stationery Office.

DES (2011) *National strategy for higher education to 2030: report of the strategy group*. Dublin: Department of Education and Skills.

Department of Equality and Law Reform (1996) *Strategy for equality: report of the Council for the Status of People with Disabilities.* Dublin: Stationery Office.

Dewey, J. (1916) *Democracy and education: an introduction to the philosophy of education*. New York: Macmillan.

Dewey, J. (1938) *Experience and education*. New York: The Macmillan company.

Engeström, Y. (1987). *Learning by expanding: an activity- theoretical approach to developmental research*. Helsinki: Orienta-Konsultit.

Engeström, Y. (2001). *A new introduction to learning by expanding: an activity-theoretical approach to developmental research*. Helsinki: Orienta-Konsultit.

Field, J. and Morgan-Klein, N. (2014) 'Disability and learner identities in Scotland' in F. Finnegan, B. Merrill and C. Thunborg (eds) *Student voices on inequalities in European higher education: challenges for policy and practice in a time of change*. London: Routledge.

Finnegan, F., Merrill, B. & Thunborg, C. (eds) (2014) *Student voices on inequalities in European higher education: challenges for policy and practice in a time of change*. London: Routledge.

Fleming, T. & Finnegan, F. (2011) *Non-traditional students in Irish higher education: a research report*. Brussels: RANLHE.

Fleming, T., Loxley, A., Kenny, A. and Finnegan, F. (2010) *Where next? A study of work and life experiences of mature students.* Dublin: Combat Poverty Agency.

Gannon B. and Nolan B. (2006) *The dynamics of disability and social inclusion in Ireland*. Dublin: The Equality Authority and the National Disability Authority.

Gardner, H. (1999) *Intelligence reframed: multiple intelligences for the twenty first century*. New York: Basic Books.

Gilligan, C. (1982) *In a different voice: psychological theory and women's development*. Cambridge, Mass.; London: Harvard University Press.

Goode, J. (2007) ''Managing' disability: early experiences of university students with disabilities', *Disability & Society* 22 (1): 35-48

Government of Ireland (1993) *Report of the Special Education Review Committee*. Dublin: The Stationery Office.

Government of Ireland (1997) *Universities Act.* Dublin: The Stationery Office.

Government of Ireland (1998a) *Employment Equality Act*. Dublin: The Stationery Office.

Government of Ireland (1998b) *Education Act.* Dublin: The Stationery Office.

Government of Ireland (1999) *National Disability Authority Act*. Dublin: The Stationery Office.

Government of Ireland (2000) *Equal Status Act.* Dublin: The Stationery Office.

Government of Ireland (2005) *Disability Act*. Dublin: The Stationery Office.

Government of Ireland (2006) *Institutes of Technology Act*. Dublin: The Stationery Office.

Grantley G. (2000) 'Towards inclusion in university of people with intellectual disabilities'. Paper presented at *ISEC conference, Including the Excluded.* Manchester, 24–28 July 2000. Available online: http://www.isec2000.org.uk/abstracts/papers_g/grantley_1.htm >Accessed 27/9/13.

Holloway, S. (2001) 'The experience of higher education from the perspective of disabled students', *Disability & Society,* 16(4): 597–615.

Hurst, A. (1996) 'Reflecting on researching disability and higher education', in L. Barton (ed.) *Disabilities and society: emerging issues and insights.* London: Longman.

Hurst, A. (1998) (ed.) *Higher education and disabilities: international approaches.* Aldershot, Hants: Ashgate.

Hughson, E.A., Moodie, S. and Uditsky, B. (2005) *The story of inclusive post secondary education in Alberta. Final research report 2004-2005.* Available online: <http://steps-forward.org/pdf/The_Story_of_Inclusive_Post_Secondary_Education_in_Alberta.pdf>. Accessed 15/10/13.

Hunt, R. (2013) *Listen to me: the learning and experience of adults with intellectual disabilities using autobiographical digital narratives.* Unpublished MEd thesis: Maynooth University.

Iacono, T. (2006) 'Ethical challenges and complexities of including people with intellectual disability as participants in research', *Journal of Intellectual & Developmental Disability,* 31(3), 173–179.

Iacono, T. and Murray, V. (2003) 'Issues of informed consent in conducting medical research involving people with intellectual disability', *Journal of Applied Research in Intellectual Disabilities* (16) : 41–51.

Keane, E. (2009). 'Frictional' relationships tension in the camp: focusing on the relational in under-represented students' experiences in higher education'. *Irish Educational Studies, 28*(1): 85-102

Kittay, E.F. (1999) *Love's labour: essays on women, equality and dependency.* London, New York: Routledge.

Kittay, E.F and Carlson, L. (eds) (2010) *Cognitive disability and its challenge to moral philosophy.* Chichester West Sussex; Oxford; Malden, MA.:Wiley-Blackwell

Knowles, M. S. (1970). *The modern practice of adult education: andragogy versus pedagogy.* New York: Association Press.

Kubiak, J. and Espiner, D. (2009) 'Pushing the boundaries of inclusion within third level education', *Frontline of Learning Disability* (74): 8-9.

Lave, J. & Wenger, E. (1991) *Situated learning: legitimate peripheral participation.* Cambridge: Cambridge University Press.

Lowe, T. and O'Donnell, P. (2008) **'**To be or not to be that is the question: disabled students in third level education in Ireland' in L. Barton, L. and F. Armstrong (eds) (2008) *Policy, experience and change:cross cultural reflections on inclusive education*. No place: Springer.

Lynch, K., Baker, J., Lyons, M., & Cantillon, S. (2009) *Affective equality: love, care and injustice*. Basingstoke: Palgrave Macmillan.

McDonnell, P. (2000) 'Integration in education in Ireland: rhetoric and reality' in F. Armstrong, D. Armstrong and L. Barton (eds) *Inclusive education: policy, contexts and comparative perspectives*. London: David Fulton.

McDonnell, P. (2003) 'Education policy and disability' in S. Quin and B. Redmond (eds) *Disability and Social Policy in Ireland*. Dublin: University College Dublin Press.

McIntyre, A. (1999) *Dependent rational animals: why human beings need the virtues.* London: Duckworth.

McVilly, K. and Dalton, A. (2006) 'Commentary on Iacono', *Journal of Intellectual & Developmental Disability*, 31(3): 186–188

Mercer, G. (2002) 'Emancipatory disability research' in C. Barnes, M. Oliver and Barton, L. (eds) *Disability Studies Today*. Cambridge: Polity.

Merrill, B. and West, L. (2009). *Using biographical methods in social research*. Los Angeles; London: SAGE.

NDA (National Disability Authority) (1996) *A strategy for equality: report of the Commission on the Status of People with Disabilities*. NDA: Dublin.

Available online <http://www.nda.ie/cntmgmtnew.nsf/0/9007E317368ADA638025718D003722 24> Accessed 23/9/13

NOEAHE (National Office for Equity of Access to Higher Education) (2004) *Achieving equity of access to higher education in Ireland: Action plan 2005-2007.* Dublin National Office for Equity of Access to Higher Education: The Higher Education Authority.

NOEAHE (2006) *Towards the best education for all: an evaluation of access programmes in higher education in Ireland.* Dublin: National Office for Equity of Access to Higher Education; The Higher Education Authority.

NOEAHE (2010) *National plan for equity of access to higher education 2008 –2013: Mid-term review*. Dublin: National Office for Equity of Access to Higher Education; Higher Education Authority.

Noddings, N. (2003). *Caring: a feminine approach to ethics & moral education* (2nd edn). Berkeley, Calif.; London: University of California Press.

Noonan, M. (2012) 'An inclusive learning initiative at NUI Maynooth: the search for a model of best practice for integrating students with intellectual disability', *The Adult Learner: The Irish Journal of Adult and Community Education*: 107-114.

O'Brien, P., Shevlin, M., O'Keeffe, M., Kenny, M., Fitzgerald, S., Curtis S. and Kenny, M. (2009) 'Opening up a whole new world for students with intellectual disabilities within a third level setting', *British Journal of Learning Disabilities*, (37): 285–292

O'Brien, P., Shevlin, M., O'Keeffe, M., Kenny, M., Fitzgerald, S., Edwards, S. and O'Shea, A. (2008) *Inclusive education: a tertiary experience and transferable model? Lessons learned from the Certificate in Contemporary Living Programme.* Dublin. Dublin: TCD.

O'Brien, P., Shevlin, M., O'Keefe, M., Fitzgerald, S., Curtis, S. and Kenny, M. (2009) 'Opening up a whole new world for students with intellectual disabilities within a third level setting', *British Journal of Learning Disabilities*, 37(4): 285-292.

O'Connor, B., Kubiak, J., Espiner, D. and O'Brien, P. (2012) Lecturer Responses to the Inclusion of Students With Intellectual Disabilities Auditing Undergraduate Classes, *Journal of Policy and Practice in Intellectual Disabilities* 9(4): 247-256

Oliver, M. (1997) 'Emancipatory research: realistic goal or impossible dream?', In C. Barnes and G. Mercer (eds) *Doing Disability Research.* Leeds: The Disability Press.

OECD (Organisation for Economic Cooperation and Development) (2003) *Disability in Higher Education*, Paris: OECD.

OECD (2012) *Education at a Glance: OECD Indicators,* Paris: OECD.

Quin, S. and B. Redmond (eds) *Disability and social policy in Ireland,*
Dublin: University College Dublin Press.

Riddell, S. (1998) 'Chipping away at the mountain: disabled students' experience of higher education', *International Studies in Sociology of Education*, 8 (2): 203–222.

Rogers, C. R. (1983). *Freedom to learn for the 80's* (Rev. ed.). Columbus, OH.; London: Merrill.

Shevlin, M., Kenny, M. and McNeela, E. (2004) Participation in higher education for students with disabilities: an Irish perspective, *Disability and Society,* 19(1): 15-300

Skilbeck, M. and Connell, H. (2000) *Access and equity in higher education: an international perspective on issues and strategies*. Dublin: Higher Education Authority.

Thomson, A. (2006) 'Four paradigms transformations in oral history', *The Oral History Review* 34(1): 49–70.

Tinklin, T. and Hall, J. (1999) Getting round obstacles: disabled students' experience in higher education in Scotland', *Studies in Higher Education*, 24(2):183-194

Trow, M. (1973) *Problems in the transition from elite to mass higher education*, Berkeley, CA: Carnegie Commission on Higher Education.

UN (The United Nations) (2006) *Convention on the rights of people with disabilities.* New York: UN Available online: <http://www.un.org/disabilities/convention/conventionfull.shtml>. Accessed 13/10/13.

UNESCO (United Nations Educational, Scientific and Cultural Organization) (2005) *Guidelines for inclusion: ensuring access to education for all*, Paris: UNESCO.

UPIAS and DA (Union of the Physically Impaired Against Segregation and the Disability Alliance) (1975) *Fundamental principles of disability*. London: UPIAS/DA.
Available online: < http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf>
Accessed 24/9/13.

Vygotsky, L. (1962) *Thought and language*. Cambridge, Mass.: MIT Press.

Vygotsky, L. (1978) *Mind in society: the development of higher psychological processes*. Harvard: Harvard University Press.

Walmsley, J. (1998) 'Life history interviews with people with learning disabilities', in (eds) J. Perks and A. Thomson, *The oral history reader.* London; New York: Routledge.

Wenger, E. (1998) *Communities of practice: learning, meaning and identity.* Cambridge: Cambridge University Press.

West, L. (1996) *Beyond fragments: adults, motivation, and higher education: a biographical analysis*. London: Taylor & Francis.

Appendix I: Invitation to an interview on student experience on the ILI in Maynooth University

Dear XXXX,

We would like to invite you to take part in an interview about your experience as a student at Maynooth University.

We are holding these interviews because we want to hear what you have to say about Maynooth University and to learn from this. The interviews will be conducted by Dr Fergal Finnegan from the Department of Adult and Community Education and Jean Cassidy a manager in KARE. XXXXX will be there to support you (her phone number is XXXXX). The interview will be very informal and relaxed and to give you an idea of what type of questions will be asked I have enclosed a document which gives a list of the sort of things we might discuss on the day. Anything you say in the interview will be treated confidentially.

In order to make your decision about whether you want to participate in the research it is important that you know exactly what the research is for and how the interview material will be used afterwards. I have enclosed a document which will give you the necessary information about this. Please take some time to read the documentation with your support worker and discuss it with them. If following this you are willing to take part please sign the consent form and bring this with you to the interview.
If you have any queries or concerns please contact XXXX

The interview will take place at XXXX

Yours Sincerely,

_____
Fergal Finnegan

Appendix II: Background Information document and consent form

Research Study of Inclusive Learning Initiative (ILI) at Student Level

Information Sheet and Consent Form for Interviews with Inclusive Learning Initiative Students

The Inclusive Learning Initiative (ILI) is an initiative between NUI Maynooth and disability agencies KARE, St. John of Gods, Stewards Hospital and Camphill.

The students are studying modules in:

- Department of Music
- Department of Media Studies
- Department of Design Innovation
- Department of Early Irish
- Department of Anthropology
- Department of Community and Youth Work
- Department of Adult and Community Education

Information for students on the Inclusive Learning Initiative (ILI)
Research Study

What is happening?	Inclusive Learning Initiative (ILI)* Research Study*
	*Word meanings: *ILI is short for Inclusive Learning Initiative, the initiative that you are a student on in university. *Research Study Using ways such as interviewing to find out information on something. In this case it is people.

What is it about?	This Research Study is about the students registered on the ILI. It will be one part of other research going on in the ILI. Students departments and campus supports will also be looked at in other research for the study.
Why is this research study being done?	To collect information on the ILI. To look at the student experience/ journey in the ILI. To look at the supports ILI students were given. To see what changes and improvements need to be made to the ILI. To see what positives the ILI has given its students. To see what challenges face the ILI and the students. A researcher will be doing the research study. *Researcher – Someone who finds out the information and presents the information.
What do I do in this research study?	In this research study will we ask you to take part in an interview. The interviews will be held on the university campus at a time that suits you. Interviews will last for about 45 minutes. The amount of interviews depends on the information the researcher needs and the time the student is willing to give. You will be asked some questions about your experience of first year on the Inclusive Learning Initiative (ILI) and your first year in college.
What will happen in this research study?	Your interview with the researcher will be recorded. The recording will be kept on an audio file. An audio file records the voice and is kept on a computer. You have the choice if you would like support to say what you would like to say in the interview. This support person will be called an advocate.

	There will be a support person in the interview with you who will act as a supervisor.
	This is to make sure the information given by the student his his/her own.
	It is to make sure that the researcher is doing the interview in the right way.
	Effort will be made to make sure the ILI students are protected in this study.
	If a student is stressed or upset in any way, psychologists / counsellors from KARE, St John of Gods and the Maynooth University Counselling service will be there to support the students.
What happens if I do not want to take part in this research study?	You have the choice if you want to take part in this research study.
	If you have any questions you can contact a person from the research team. The research team are the people who are doing this research study. Their information is on this form.
	If you **do** want to take part we will ask you to sign your name on a consent form. A consent form shows that you want to take part in the study.
	You will sign your name with a support person in your life.
What happens to the information that I give?	You will get a copy of the information you have given in your interview(s).
	Your name will be anonymous in the study.This means that people who read the report will not know who you are.
	The information that you give will be written up in a report that will be published*.
	The information that you give will be kept for the study.
	It will be kept only by the research team for the study.
	It will be kept on computers that need a special password.
	You will get a copy of the final report.

	You have the choice to get the final report in an easy to read way if you like..
	*Published means – the final report will be made available to other people to read.
	The report may also be used in presentations or conferences where people will hear and see the information from the research study.
	You will be informed before if the research study is going to be presented.
Who do I talk to if I want to know more about this research study?	You can talk to the ILI Research Team about anything to do with this research study.
	This information is below.
The Student Researcher Information	**Name:** Dr Fergal Finnegan
	Address: Department of Adult and Community Education, Education House, National University of Ireland Maynooth Maynooth Co. Kildare

During your time in this study if you feel the information that you were given about this study has not been followed in any way, or you are unhappy about the process, please contact:
The Secretary of the National University of Ireland Maynooth Ethics Committe at:

    Email:Research.ethics@Maynooth University.ieOR Telephone: 01 708 6019

It is important to know that your concerns will be looked at in a sensitive way.

Name of Student (in block letters)

_____

Signature_____**Date**   /   /

Name of Student Support Person (in block letters)

_____

Relationship to student

_____

Signature_____**Date**   /   /

Researcher
--   **Date**

    /   /

Appendix III: Schedule of questions sent to the students with the consent form

ILI: Researching Student Experience July 2013

These are the sort of questions that will be asked in the interview.

Can you tell a little bit about yourself? (Where you are from, your age and what you like doing etc.).
Can you tell me about your education before college?
Why did you want to come to college?
When you got the letter from the college saying you had a place as student how did you feel?
What subjects are you studying?
What did your family say to you when you started college?
What did your friends say to you when you started college?
What were the first few weeks in college like?
What did you find enjoyable in your first year?
What did you find most challenging in the first year?
At the end of first year what was the most important thing that you had learnt in college?
Can you describe your typical day in Maynooth University this year?
Please tell me a little about the things that you do with your college ILI Facilitator?
How do you find working with the ILI Facilitator ?
What are the other students in your class like?
What have you learnt from the other students?
Please tell me about working with your lecturers.
How do you think going to college has changed you?
Do you think it has changed the way your family see you?
Can you please tell me about your support persons in college? (University staff and student volunteers).
What is the difference between college and your previous experience of education?
What sticks out in your mind as the best thing that has happened at college?
What advice would you give a new student coming to college?
What advice would you give a new lecturer working with students in college?
What advice would you give new facilitators who will work to support students in college?
What is the most difficult thing about going to college?
What plans do you have for the future?
Is college important to these plans?
Has college changed the way you see yourself?
Do you have any other comments or suggestions?

Appendix IV easy to read summary of the report used in student consultations

HAVE I LISTENED TO YOU?

As you know I have written a report about how you see college. Thanks again for your time and help. Before I finish writing it I want to check if I have been listening to you with care and attention. I want to know what I have written is right.

I will meet you to talk about the report and answer your questions. I have written a summary of the report here so you can think about this before we meet.

Remember I will change the report if you want.

What is in the report?

The report talks about what you said to me in the interviews.
It talks about the ILI.
I explain how I did the research.

Why was the report written?

The ILI team asked me to write the report. I want to know how you see college.
I want to know what you think works on the ILI and what does not work. Having a report means other people can learn from you and the ILI.

It is very, very important........

It is important that you did not feel forced to do an interview.
It is important that the interviews were comfortable.
It is important that I explained what was happening clearly.
It is important that we talk about what I learnt from you.

What you say about college:

The report says each of you is different and each of you talks about college differently.
The report says you like being in college a lot
It says that you have learnt a lot and you enjoy learning new subjects.
That you say one of the best things about being in college is meeting new people.
It says that college has given you more confidence.
You think it has made you more independent.
It says you think it is good to have the same chances as your family and friends. Your family are proud of you.
It says you think [name of ILI Facilitator] and the ILI
team help you a lot. It says you think [name of ILI
Facilitator] is doing a very good job
The report says you think the volunteers are a good support.
It also says that some of you talked about being friends with the volunteers.
It says the most of the lecturers and tutors are helpful.
It says having supports are good but we should remember that you are determined and work hard.

It says college is not always easy because.....

The assignments in first year were hard for most of you.
Getting to know people is not always easy. Some of you had problems getting comfortable.
That telling lecturers or other students about disability can be hard.
Not everyone in college understands disability or what the ILI is.

What the report says about the ILI:

You think the ILI is a good thing for you and for the college.
It says other people could learn from it.
It says [name of ILI Facilitator] is very
important in the ILI.
It says [name of ILI Facilitator]a is very
busy.
It says you all like the ILI but some of you want to talk about it to other people and some of you prefer not talking about it.

In the report I say that after meeting you I think:

Finding ways to give more opportunities to students with disabilities is important.
We all need to work hard to understand how we can make college a more comfortable place for everyone.
We have to work hard to find new ways of talking about disability and education.
We need to think about what you say about teaching and learning.

The report looks at how I did my work

I say most of the information comes from talking to you. I listened to the interviews a few times and I read them slowly. I did this to find out what you think is important.
I also learnt from [names of ILI staff].
I also learnt by looking at some of your college work and some books and films you showed me.
I learnt by listening to interviews you did with ILI staff last year.
I looked at what you and [name of ILI Facilitator] did together.

I also write about

What the ILI is and why it was started.
Why I did the research.
What other people are saying about inclusive education.
What is happening in Irish colleges.
I also talk about what students in other colleges say.

THANKS A LOT !

I will sit down and talk with you very soon if you are ok with that and see what questions or comments you have.