An investigation of issues and challenges facing programmes available to adults with intellectual disabilities in Ireland aimed at supporting the transition beyond secondary education.

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A dissertation submitted to Trinity College Dublin in part fulfilment of the degree of Master of Science in Disability Studies

Under the supervision of Prof. Robbie Gilligan
Declaration

I hereby certify that the material submitted in this thesis towards the award of Masters in Disability Studies is entirely my own work and has not been submitted for any other academic assessment other than part fulfilment of the award named above. Permission is given to Trinity College Dublin to lend or copy this thesis.

Signature of Author: _________________________________

Date:__________________________
Summary

This applied research assignment originates from an emphasis of new national and international legislation and policies, in Ireland. A focus has been placed on supporting people with intellectual disabilities to move from congregated settings to more socially inclusive, community based roles. While Government directives have emphasised the importance of this change, latest statistics indicate that progress has been slow to date. A number of strategies have been developed in recent years to tackle this lack of progress. One such strategy involves disability services developing and implementing programmes aimed at supporting the transition of people with intellectual disabilities, into options after secondary education. As these programmes remain under researched, the aim of this research assignment is to discover challenges and issues currently facing these programmes.

A qualitative method was used to collect data within this research assignment. Semi-structured interviews were conducted with seven programme managers in order to provide clarity in relation to the research question. The knowledge and experience of programme managers gave an insight into the challenges and issues facing these programmes.

The findings of this research include; aspects of the challenges facing programmes in achieving compliance with new legislation and policies, issues resulting from attempting to provide an educational programme within a disability service and programme participants achieving appropriate progression after the transition programmes conclude. The research highlights the challenges presented by these thematic headings and the impact that they have on the programmes.
Additionally, programme managers revealed possible areas of development for consideration, in order for programmes to meet the aim of transitioning people with intellectual disabilities into socially-inclusive, community based options and as a result, comply with the legislation outlined.

In line with best practice identified in the literature, the research outlines a cost-effective, practical framework to facilitate the development of disability services providing these transition-based programmes. The research concludes with some suggestions for possible directions for further research.
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<th>Description</th>
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<tr>
<td>FETAC</td>
<td>Further Education and Training Awards Council</td>
</tr>
<tr>
<td>HIQA</td>
<td>Health Information and Quality Authority</td>
</tr>
<tr>
<td>HSE</td>
<td>Health Service Executive</td>
</tr>
<tr>
<td>IDEA</td>
<td>The Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>NDA</td>
<td>National Disability Authority</td>
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<td>PWD</td>
<td>People With Disabilities</td>
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<td>PWID</td>
<td>People With Intellectual Disabilities</td>
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<td>RT</td>
<td>Rehabilitative Training</td>
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<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UNCRPD</td>
<td>UN Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>USA</td>
<td>The United States of America</td>
</tr>
</tbody>
</table>
“Everything changes and nothing stands still.” Heraclitus
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I would like to acknowledge and thank my thesis supervisor Prof. Robbie Gilligan whose research expertise was insightful and invaluable and Dr. Edurne Garcia Iriarte for her support, feedback and direction; during the Masters programme of which this thesis was a part.

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Chapter One: Introduction

1.1 Background

Transition is defined by the Oxford Dictionary (2014) as ‘The process or a period of changing from one state or condition to another’.

When considering this definition in purely scientific terms, transition refers to change and change is the only thing that remains constant. The change referred to in the following research assignment, relates to the lives of people with intellectual disabilities moving to life after secondary education concludes.

A variety of definitions of transition and transitioning appear in the literature. The author took his understanding of the process of transitioning within the literature on transitioning in the field of intellectual disability research from Wehman (2006), who defines transitioning as a process whereby the life changes that occur in the lives of young adults as they move from school environments to independent living and work environments.

This definition provides a key framework for the following research assignment as it focuses upon programmes designed to specifically support the transitional period of the lives of people with intellectual disabilities after secondary school.

1.2 Context

The primary focus of the following research is the study of transition programmes for people with intellectual disabilities after secondary education in Ireland. The specific
area of interest within the research is to investigate the challenges faced by these programmes which are provided by Intellectual Disability Services in Ireland.

With a wealth of recent policy and legislation driving towards a culture of inclusiveness for people with disabilities these transition programmes may be an essential development in supporting this drive, on a local level and possibly on a global level.

These programmes are unique in that they are provided by Intellectual Disability Services in Ireland and are funded under Section 38 of the 2004 Health Act by the Health Service Executive. The aim of these programmes is to provide Rehabilitative Training (RT) which focus upon on developing a person’s core life skills, social skills and basic work skills. (Enable Ireland 2014)

The author’s reasons for choosing this area of study can be attributed to a growing appreciation of the importance of attempting to support transition for people with disabilities after secondary school, a direct result of the author having undertaken the Masters in Disability Studies programme. The heightened awareness of the field of disability studies led the author to reflect on the importance of the period of life for people with disabilities (PWD) after leaving secondary education. Supporting this period of life appropriately may assist the move towards a more socially inclusive society, as suggested by Benz, Lindstorm and Yovanoff (2000).
This is an important area of study due to Ireland’s recent history, which has placed a significant emphasis upon meeting the individual needs of people with disabilities. This is prevalent in the Disability Act 2005 and the Education for Persons with Special Needs Act 2004. More recently Ireland has become a signatory to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which promotes full participation at all societal levels for people with disabilities.

Initiatives such as service-provided transition programmes aimed at supporting PWD to access community-based outcomes after secondary school are an important means of assessing progress in this area thus far, however research has been very limited on the programmes themselves.

To date, there has been no research published on these particular service-provided transition programmes to determine what their strengths and weaknesses are, or indeed to document any learning taken from their development and implementation since their inception. The author’s initial reading in the area of transition programmes, highlighted the significance of supported transitioning in the lives of people with intellectual disabilities (PWID) (O’Brien et al. 2011) and the importance of the period when reaching ‘adulthood’ in the lives of PWID (Nuehring and Sitlington 2003). These findings, coupled with the varied reports in existence, discussing the lack of social inclusiveness of PWD after leaving secondary education in Ireland, acted as the spur to the author’s research enquiry and led the author to consider investigating the service-provided transition programmes available to PWID leaving secondary school in Ireland and to uncover what challenged these programmes are currently facing.
This is an important area of study for a variety of reasons. Firstly, despite the importance of supported transitioning for PWID as highlighted by the research, a dearth of research currently exists on service-based transition programmes; secondly, the learning gained from this research may inform future initiatives undertaken in Ireland which share the same goals as the programmes being investigated in this research; finally the research may provide an indicator of the current state of Ireland’s transition towards a more socially inclusive society for PWD.

1.3 Aims

The aims of the research are:

- To explore the challenges facing the implementation of programmes compliant with national and international legislation and policy that are aimed at supporting adults with intellectual disabilities in Ireland during the transitional period after secondary education.

- To identify issues for consideration with regards to the future development of the programmes presently being discussed.

1.4 Objectives

The objectives of the research are:

- To conduct a review of the literature in relation to national and international legislation and policies on the appropriate means of supporting people with intellectual disabilities during the transitional period after completion of secondary education.
• To gather data, through interviews with seven programme managers involved in the implementation of a number of programmes, with regards to the challenges currently facing the programmes.

• To discover through the interview process with the programme managers, issues for consideration in the future development of the target research programmes.

1.5 Research question

The research is guided by the following research question:

“What issues and challenges are facing programmes in Ireland developed to support adults with intellectual disabilities transitioning into options after secondary education, and what issues should be considered during the future development of these programmes?”

1.6 Structure of the research assignment

This chapter concludes with an outline of the rest of the research assignment:

Chapter two provides a review of current literature within and Irish and global context focusing on programmes aimed at supporting PWID’s who are transitioning from secondary education.
Chapter three outlines the research methodology. It describes the design used in the research assignment and outlines the method of data collection and analysis. It looks at the limitations of and ethical considerations of the research assignment.

Chapter four presents the key findings from the analysis of the themes that emerged across the qualitative data in this research assignment.

Chapter five discusses the findings in relation to the research question and the broader literature. The implications and recommendations that became evident from the research is discussed and outlined.

Chapter six concludes the research assignment along with the limitations of the research assignment, the author’s reflection on the learning experience of writing the dissertation and the final conclusion.

A list of appendices and references are included at the end of this dissertation. Next follows the literature review chapter which analyses the relevant literature on supporting transition from secondary education for PWID’s.
Chapter Two: Literature Review

2.1 Introduction

An essential part of this body of work is the construction of a theoretical frame of reference that facilitates primary research, as Hart (1998 p1) states; that the review is a part of the author’s academic development and assists an individual in becoming an expert in the field. This Chapter will review some of the literature pertaining to Irish and International definitions of key concepts in disability studies. Comparative views of the concept of transition for PWID, current international legislation and policy providing a context to understand change within Irish Disability sector, along with current research on transition programmes for PWID after leaving secondary education from an Irish and international perspective. The literature review includes documentation from the 1980’s to the present day in order to contextualise the research on transition programmes within a period when some of the most influential policy and legislative changes occurred internationally and subsequently in Ireland.

In addition to sourcing printed material from the field of education and disability studies through Trinity College inter-library services; searches were conducted through electronic databases (Scopus; Web of Science; CINAHL; EMBASE). The research reviewed is limited to research published within the past thirty-five years.

The area of research is exploring supported transitioning for adults who have recently completed secondary education with intellectual disabilities in Ireland. This topic can best be addressed with reference to the following key areas.

- Definitions relevant to the research topic,
- Views of the transition from childhood to adulthood,
- Policy and legislation driving change,
- And transitioning programmes for adults with intellectual disabilities in Ireland and globally.

These are the areas of literature that author considers are legitimate topics to be reviewed for a comprehensive understanding of the research subject. This framework of literature will provide a solid foundation into the background and complexities of the area of research. Thus, allowing the author to conduct the research proposed in a contextualised manner.

The research presents a review that utilised a broad approach to the select of papers to be used in the present research. This included computerised searches using the terms transitioning, post-secondary, post-education and adulthood in conjunction with the terms, mild intellectual disability, mild mental handicap and mild learning disability.

This allows for the various terminology used to describe intellectual disability along with helping to gain an international perspective. These words covered the essential elements and enabled the sourcing of articles relevant and necessary to complete this research.

2.2 Definitions

In order to conduct this research we must first explore the meanings behind specific terminology used within the research question.
2.2.1 Disability

The word ‘disability’ applies to a wide range of people and is universally acknowledged to be constantly evolving and difficult to define. ‘Disability is complex, dynamic, multidimensional, and contested.’ (World Report on Disability 2011 p3). It is important to define the term disability, as a framework can then be established enabling supports to be offered to those who may require it. Article One of The United Nations Convention on the Rights of Persons with Disabilities (2007) offers the following definition: ‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’

2.2.2 Intellectual disability

Narrowing down the field of disability under investigation is more challenging as currently there is not a standard definition or universal terminology employed in the field of intellectual disability. However the term ‘intellectual disability’ is now emerging as the preferred term for what is referred to as ‘mental retardation’ in the United States and ‘learning disability’ in the United Kingdom. In Ireland the term intellectual disability has become the more utilised phrase used by professionals in the field.

Intellectual disability is considered a lifelong condition with multiple causes and origins. The World Health Organisation (WHO), definition is generally accepted: ‘a condition of arrested or incomplete development of mind characterised by the impairment of skills and overall intelligence in areas such as cognition, language,
motor and social abilities’ (2000 p1). Aetiology of intellectual disability can be attributed to many sources, those of a known organic or those of which are unknown (Healthcare Commission 2007).

2.2.3 Transitioning

As discussed previously, transition refers to change. In this context the research is considering the transition from the mandatory education available to all until the age of 18, to life after this period. This will be referred to as life after secondary education.

The term transition has been commonly used to describe the crucial task of moving from the protected life of a child to the autonomous and independent life of an adult. Individuals vary substantially in their experiences and the rate at which they transition. There are a number of different ways of theorising the transition to adulthood but the literature has predominantly focused on two areas: models based on life phases (child to adult) and models based on institutional status transition.

(O’Brien et al. 2011 p199)

In terms of institutional status transition, three specific transitions are highlighted by Mitchell (1999):

- School to work.

- Housing (moving out of the family home).

- Domestic (movement from ‘family of origin’ to ‘family of destination’).

(as cited in ibid. 2011 p21).
2.2.4 Irish service provided transition programmes

The programmes under review are service provided programmes in Ireland funded by the Health Service Executive with the aim of supporting this transitional period.

According to the Health Service Executive (H.S.E.), these programmes focus on the development of an individual's life skills, social skills and basic work skills with the objective of enhancing the trainee's quality of life and general work capacity.

(Citizen’s Information 2014)

The HSE has appointed Directors of Disability Services who are responsible, among other things, for the delivery of rehabilitative training services. The HSE have teams of guidance counsellors who offer information, advice and guidance on HSE training services (Citizen’s Information 2014). However, programmes are setup and run autonomously by services.

2.3 Transitioning from childhood to adulthood

The transition period from school to the next step in life plays a significant role in defining one’s future. This period, which generally coincides with reaching ‘adulthood’, may define one’s educational journey, employment path, or the role one plays in society. One of the most important transitions in the lifespan is the movement from “childhood” to “adulthood” (Lehmann and Konstam 2011).
2.3.1 Transition into adulthood

Emerging adulthood is the term used by Arnett (2007) to describe the crucial transitioning phase between childhood and young adulthood that is defined as beginning at 18 and finishes at 25. This transitional period moves from a person depending on their parents for food, clothing, and housing to more independent thinking and choice. It is considered a norm that entering adulthood will bring a level of responsibility for sustaining oneself, and this has major implications for behaviour and patterns of thinking.

“As young people are expected to enter college or the workforce, financial responsibility gradually shifts from their parents to themselves. They continue to try out many behaviours and self-concepts (just as teens do), but this experimentation is tinged by the realization that soon they will have to stabilize their behaviour and assume more responsibility for their own livelihoods.” (Feist and Rosenberg 2009 p200)

According to Arnett (2007) the key transformations during emerging adulthood are dealing with increased responsibility and recognizing the need to make decisions about some of the things one has been exploring.

Finding agreement within the literature with regards when this transformation to ‘adulthood’ is finally reached is a challenging task. A few cultures remain which have rituals to mark this change to ‘adulthood’, however in a majority of modern societies there is a reliance on the assumption that certain responsibilities occur when the person reaches a certain age. Usually the transition to young adulthood occurs in the
20s, though certain life transitions represent more significant markers than age alone (Arnett 2007). For instance, in young adulthood, financial and living arrangements are expected to have been decided on, and many people marry or form long-term partnerships. Thus, emphasising the need for the individual to become increasingly engaged with the wider society (Burt and Masten 2010).

What is noted throughout the research on moving to ‘adulthood’ is that this period is a challenging and sometimes difficult time for those people expected to drastically change their personality. Davis notes, ‘that this challenging period of time is rife with life-impacting risks […] and society expects adults to mature and take on the mantle of adulthood at this time’. (2003 p12)

### 2.3.2 Transition into adulthood for PWID

The author will attempt to view Arnett’s conceptualisation of the transformation to adulthood for PWID. According to May, it appears to be widely considered that adolescents with disabilities face the same multitude of changes in their transition to adulthood as typically developing peers, while also facing additional challenges (2000).

These additional challenges are of wider scope, longer duration, and attenuated experiences than for those without an intellectual disability. (Foley et al. 2012)

A major finding of a study in the United Kingdom cited by Van Naarden et al. (2006) highlights the bureaucratic aspects involved in the transition for between service settings that is often experience, as a major difference for PWID’s. This transitional
aspect often involves a shift from segregated settings and extra supports in the form of specialist professionals, social services, and formal supports to mainstream educational and employment settings.

This change of service settings commonly experienced by PWID is referred to as adding additional challenges to this difficult transitional period. Families and caregivers have reported transition as a time of upheaval, stress and important decisions, and there is much confusion about services available. (Caton and Kagan 2006)

Research also indicates that other challenges exist for PWID during this period. These include the bias towards people with mild intellectual disability, the difficulty of accurately describing the psychological experience of transition, and the strong focus on employment and autonomy alone. (Clegg et. al 2001)

The impact of unsuccessful transitions for adults with PWID may ultimately lead to PWID not occupying an adult social role. Whilst this may be attributable to impairment and activity limitations, environmental factors may impose constraints beyond these factors such as barriers arising from gender, economic, and/or racial disparities regardless of impairment.

Due to the complexities of transitioning, exploring and facilitating the complex and multi-faceted transition process for young PWID has now become an important
concern internationally for service providers and researchers working within this area. (Van Naarden et al. 2006).

### 2.3.3 Supported transition programmes into adulthood for PWID

Hudson describes the transition for PWID after they school leave as the invisible transition. This term stems from the fact that the paths of PWID are no longer surrounded by law, circular and guidance as to what should be done, who is responsible for this and at what point this should happen. At the heart of this is the reality that too often there are so few options available, and that whatever skills may have been acquired in the preceding years will not be put to optimum use (2006 p56). One response to this conundrum is for Governments to offer supported transition programmes.

When these programmes were originally conceptualized, many in the field focused on the transition of students with disabilities from one service system to another that is, from the educational system to the adult disability service system.

With increasing understanding of the complexity of effective transition practices, many researchers adopted a much broader conceptualisation of transition programmes (Bates 1990 ; Wehman 1996). Kohler and Field (2003) referred to this as ‘transition-focused education’. This perspective views transition as a fundamental basis of education that guides the development of all transition programs. Transition-focused programmes are guided toward adult outcomes and consist of academic development, career progression, and extracurricular instruction and activities, delivered through a variety of instructional and transition approaches and services, depending on the local
context and students’ learning and support needs. Modern research on supported transitions post-education is divided into academic, vocational and employment-based pathways (Raffe et al. 1998).

According to Wehman (1996). The concept of transition focused education and training represents a shift from disability-focused, deficit-driven programs to an education and service-delivery approach based on abilities, options, and self-determination. This shift reflects a change in wider societies’ views of disability and the drive to increase social inclusion of PWD.

Within this changing landscape, the complexities of transitioning into adulthood for PWID, requires careful consideration to be given to this form of transition support. Although there is no definitive format for these programmes, Forbes et al. (2002) identify components of best practice regarding supported transition programmes for PWID:

- Specific service provision.
- Development of skills of self-management and self-determination.
- Supported psychosocial development.
- Involvement of young people.
- Peer involvement.
- Support for changed relationships with families.
- Provision of choice.
- Provision of information.
- Focus upon young person’s strengths for future development.
The author will examine implementation of supported programmes, in various contexts, in the following subchapters, along with a review of transition programmes both in Ireland and Internationally.

2.4 Transition programmes in an Irish context

The author will review transition programmes in an Irish context by providing an overview of the history of disability in Ireland, the current status of PWID in Ireland, legislation and policy driving changes in Ireland and a review of current programmes provided by the Government of Ireland.

2.4.1 Disability in Ireland

Since the 1780’s in Great Britain, a trend towards a more tragic view of disability has existed. With people losing their function in society due to the Industrial Revolution, a need was identified in Great Britain to care for people with disabilities who no longer had a contributing role in the family home, in a more remedial way. Ireland followed this global trend towards the medical model of support and to this day still has a largely medicalised form of support for people with disabilities. ‘Up to now the dominant model of delivering rights, entitlements and resources to people with disabilities has been a medical-charitable model, which bestows discretionary services as a gift.’ (Conroy 2011 p30)

After many years of living with this medicalised model, people with disabilities and leading theorists from disability studies have highlighted the damaging effect that the model has on people with disabilities and societies understanding of disability. Carson provides a summary of this negative impact:
1. A person with disability’s inability to join in society is seen as a direct result of having an impairment and not as the result of features of our society, which can be changed.

2. When policy makers and organisational decision makers think about disability in this individual way they tend to concentrate their efforts on `compensating’ people with impairments for what is ‘wrong’ with their bodies by, for example, targeting ‘special’ benefits at them and providing segregated ‘special’ services for them.

3. This model of disability also affects the way disabled people think about themselves. Many disabled people internalise the negative message that all disabled people’s problems stem from not having ‘normal’ bodies. Disabled people too can be led to believe that their impairments automatically prevent them from participating in social activities. This attitude can make disabled people less likely to challenge their exclusion from mainstream society.

   (2009 p6)

As a result of this medicalised model, the practical meanings attached to the words ‘disability’ and ‘intellectual disability’ are starkly different from the modern definitions provided in subchapter 2.2 Definitions. According to Oliver and Barnes (2012 p11) ‘the dominant meanings attached to disability in most western industrial and post industrial societies remain firmly rooted in personal tragedy theory’.
2.4.2 Legislation and policy driving change in Ireland

Current legislation portrays a view of requirements to be provided to men and women with any form of disability, which has moved away from treating people as patients and moved towards equity for all. There has been a wealth of person centric driven legislative standards, set out internationally and nationally in Ireland. These have informed the design and creation of supported transition programmes for PWID into options after secondary education. The author has chosen to focus on a variety of documents to demonstrate this:

The United Nations Convention on the Rights of Persons with Disabilities was adopted in 2007. This Convention aims to ensure that people with disabilities have access to equal rights and where the interests of persons with disabilities may need to be protected. (UNCRPD 2007)

It marks a paradigm shift in attitudes and approaches to persons with disabilities, changing the way we look at people with disabilities from a medical perspective in which the disability is considered a problem of the individual who needs to be rehabilitated. (O’Brien et al. 2011)

The Disability Act was enacted in Ireland in 2005. This act aimed to ensure that people with disabilities have access to equal opportunities i.e. education, employment, etc. This was a measure designed to advance and underpin participation by people with disabilities in everyday life by establishing a statutory basis. An obligation was placed on public service providers to support access to services and facilities for people with disabilities to the greatest practical extent. (ibid. 2011)
From a service perspective, New Directions has been created. This is a Government directive aimed at guiding services towards the means of complying with the above legislation and best practice policies. The range of supports to which individuals will have access should equip them to:

- Make choices and plans to support personal goals.
- Have influence over the decisions which affect their lives.
- Achieve personal goals and aspirations.
- And be active, independent members of their community and society.

(New Directions 2012 p16)

New Directions is a significant document from the perspective of transition programmes for PWID leaving education. Despite not mentioning transition programmes specifically, an emphasis is placed on the promotion of programmes which promote social inclusion and person centeredness.

New Directions calls for a blurring of the boundaries between ‘special’ and ‘mainstream’ services [...]. It challenges people with disabilities to have high expectations for themselves and of their community. It also challenges families and services to adopt an attitude of positive risk-taking. It encourages providers to provide greater outcomes from their current service.

(New Directions 2012 foreword)
The Health Information and Quality Authority (HIQA) has been setup to monitor disability services compliance with the legislation and policies outlined above. At the moment HIQA inspects residential services for PWID, however in the future this legislation is aimed to focus on all services provided to PWID.

The need for a clear shift in thinking from the personal tragedy theory to a more socially inclusive and equal society for PWID is clear in the documentation and guidelines designed and implemented by the Irish Government. Disability services must respond to this paradigm shift and transition programmes have been developed as a means of responding to this shift for PWID transitioning into adulthood.

2.4.3 PWID in Ireland today

It is clear that from a Government perspective a movement towards a socially inclusive society for PWID has been established but what is the current reality of this movement for PWID in Ireland? In a recent report The National Disability Authority (NDA 2013) suggests that people with an intellectual disability in Ireland experience social, political and economic exclusion.

There are 26,066 PWID registered on the National Intellectual Disability Database (NIDD 2009), an increase of 37% since the 1974 Census (Kelly et al. 2009). Census statistics from the year 2006 shows that 7% of adults with intellectual disabilities had at this time progressed to education beyond secondary level. This is in comparison with the fact that 29% of the total population had progressed to education beyond secondary level.
These low levels of equality continue with regards to attainment of degrees. 19% of the total population have received a degree or more at third level. Only 4% of people with intellectual disabilities have received a degree or more. (Table 2.1)

From the perspective of employment, these census statistics (table 2.2) again show a lack of inclusion for people with intellectual disabilities. Only 31% of all people (excluding students) with intellectual disabilities were employed, in stark contrast with the total population statistics that indicate that 73% were employed.

Table 2.1: Progression to further education

Table 2.2: Progression to further education

(Central Statistic Office 2007)
With participation levels so low, a clear need for appropriate supports to enable PWID in Ireland to access open employment and mainstream education is required. As outlined in Table 2.3 and 2.4, of the 27,483 people with intellectual disabilities receiving supports from the government in 2012, only 1,022 people are in employment (open or supported) or third level education, which is not considered to be a ‘segregated’ setting.

Table 2.3: Service provision to those registered on the NIDD

<table>
<thead>
<tr>
<th>Service provision</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending services on a day basis</td>
<td>19133</td>
<td>69.3</td>
</tr>
<tr>
<td>Receiving 5- or 7-day residential services</td>
<td>7900</td>
<td>26.6</td>
</tr>
<tr>
<td>Resident in a psychiatric hospital</td>
<td>192</td>
<td>0.7</td>
</tr>
<tr>
<td>Receiving residential support services only</td>
<td>25</td>
<td>0.1</td>
</tr>
<tr>
<td>Receiving no service – on waiting list</td>
<td>227</td>
<td>0.8</td>
</tr>
<tr>
<td>No identified service requirements</td>
<td>130</td>
<td>0.5</td>
</tr>
<tr>
<td>Total</td>
<td>27622</td>
<td>100.0</td>
</tr>
</tbody>
</table>

(NIDD 2012)

Table 2.4: Principal day service availed of

<table>
<thead>
<tr>
<th>Service provision</th>
<th>Under 18</th>
<th>18 &amp; over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home support</td>
<td>61 (38%)</td>
<td>94 (52%)</td>
</tr>
<tr>
<td>Home help</td>
<td>0 (0%)</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>Early intervention team</td>
<td>531 (61%)</td>
<td>83 (10%)</td>
</tr>
<tr>
<td>Special needs for intellectual disability</td>
<td>359 (42%)</td>
<td>59 (7%)</td>
</tr>
<tr>
<td>Mainstream pre-school</td>
<td>6 (5%)</td>
<td>2 (0.3%)</td>
</tr>
<tr>
<td>Mainstream school</td>
<td>239 (28%)</td>
<td>44 (5.5%)</td>
</tr>
<tr>
<td>Mainstream school</td>
<td>445 (52%)</td>
<td>44 (5.4%)</td>
</tr>
<tr>
<td>Resource/Inclusion team</td>
<td>77 (9%)</td>
<td>7 (1%)</td>
</tr>
<tr>
<td>Special class – primary</td>
<td>107 (12%)</td>
<td>20 (2.6%)</td>
</tr>
<tr>
<td>Special class – secondary</td>
<td>4 (0.5%)</td>
<td>2 (0.3%)</td>
</tr>
<tr>
<td>Special school</td>
<td>298 (35%)</td>
<td>22 (2.8%)</td>
</tr>
<tr>
<td>Third-level education</td>
<td>0 (0%)</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>Rehabilitation training</td>
<td>0 (0%)</td>
<td>9 (1.2%)</td>
</tr>
<tr>
<td>Activation centre</td>
<td>0 (0%)</td>
<td>15 (1.9%)</td>
</tr>
<tr>
<td>Programme on the older person</td>
<td>0 (0%)</td>
<td>12 (1.5%)</td>
</tr>
<tr>
<td>Specialist high-support day service</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Specialist infirm care day service</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Sheltered work centre</td>
<td>0 (0%)</td>
<td>21 (2.7%)</td>
</tr>
</tbody>
</table>

(NIDD 2012)
It is clear from these statistics that PWID, can not avail of options after secondary level that are socially inclusive and equal to the options of others. Despite the intentions of the legislations and policies outlined in the previous subchapter the goal of increasing social inclusion for PWID are not being met. As defined previously service-provided programmes for PWID supporting the transition to options after secondary education have been devised as a means of tackling this and complying with the policies and legislation outlined above.

2.4.4 Service provided programmes for PWID in Ireland

Whilst a dearth of research currently exists on supported transition programmes for PWID seeking options after secondary education, some research has been conducted on service provision offered to young PWID in a general context.

Research conducted on Irish service provision for young PWID indicated that commonalities exist to what is available internationally (Wehman 2007). The national employment and vocational training agency (FÁS) and the National Disability Authority (NDA) have also examined post-school service provision for PWID in

Table 2.4: Principal day service availed of (continued)

<table>
<thead>
<tr>
<th></th>
<th>Not verified</th>
<th>MILD</th>
<th>Moderate, severe or profound</th>
<th>All levels</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Under 18</td>
<td>18 A &amp; over</td>
<td>All ages</td>
<td>Under 18</td>
</tr>
<tr>
<td>Sheltered employment centre</td>
<td>0</td>
<td>11</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Multidisciplinary support services</td>
<td>17</td>
<td>22</td>
<td>39</td>
<td>12</td>
</tr>
<tr>
<td>Centre-based day respite service</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Day respite in the home</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Outreach programme</td>
<td>1</td>
<td>6</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Other day service</td>
<td>37</td>
<td>6</td>
<td>37</td>
<td>23</td>
</tr>
<tr>
<td>Enclave within open employment</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Supported employment</td>
<td>0</td>
<td>21</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>Open employment</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Vocational training</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Generic day services</td>
<td>1</td>
<td>51</td>
<td>53</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>2191</td>
<td>106</td>
<td>2277</td>
<td>3155</td>
</tr>
</tbody>
</table>

(NIDD 2012)
Ireland since the implementation of new policies and legislation (FÁS 2006; NDA 2004). These reviews have generally found that service provision was characterized by poor coordination and fragmented services, which resulted in large, reoccurring gaps in service provision. The NDA has also highlighted that there is currently no specific needs assessment undertaken toward the end of schooling to facilitate the planning for continuing education into adulthood (NDA 2004).

Additionally, a review by Gillan and Coughlan (2010) identified a number of factors in the wider social system as barriers to successful transitions for PWID. These included:

1. A competitive Irish job market.
2. Negative employer attitudes.
3. The loss of disability benefits when a PWID works over 20 hours in a week.
4. Lack of opportunity to develop social networks.

Participants described experiencing negative attitudes from employers, in terms of lack of perceived time and interest in PWID, and a focus on profit rather than on facilitating PWID in the workplace. Research conducted by Murphy and Conroy (2007) found that there appeared to be little coordinated development of structured pathways to enable people with disabilities to progress toward open labour market employment. Haase and Byrne (2005) found that there was a considerable lack of a person-centred approach to the transition and no detailed guidance or services that aim to streamline and coordinate the transition in Ireland.

Overall a pattern emerged in the literature with regards to the necessity of increasing
research on the area of appropriate support for PWID. The amount of evidence relating to people with an intellectual disability is less than for other groups, and there should be an emphasis to address these inequalities and to develop high-quality research to identify additional supports or adjustments required that will benefit PWID (Cooper et al. 2004 p414). In addition McGrother et al. emphasises that the problem remains concerning the professional ownership of the key role in the effective provision of supports (2006 p379). Programme providers from the disability sectors need to be unified to ensure its services are appropriate, accessible and sensitive to the needs of this group (Department of Health 2001; Bigby 2004).

The Disability Act (Government of Ireland 2005) recognises the participation of people with disability in society, and their statutory entitlement to impartial independent assessment of need and Quality and Fairness (Department of Health 2001) has recommended an action plan be drawn up to co-ordinate the needs of ageing and older people. These developments are clearly a positive step for PWID, however for true progression to be made, clarity must be provided to the implementation of these guidelines; who is responsible and how can it happen.

2.5 Review of transition programmes internationally

Due to the lack of research conducted in Ireland and the desire to get an international perspective on service provided transition programmes, the author will review research from the United Kingdom (UK), the United States of America (USA) and Australia.
2.5.1 Transition programmes in the UK

Similarly to Ireland transition programmes in the UK are provided by disability specific services and funded directly by the Government. Being geographically close to Ireland and having a somewhat shared history, the UK may provide valuable learning towards the implementation and development of transition programmes for PWID in Ireland.

Transition to adulthood is highlighted as one of the key objectives of the Government White Paper, Valuing people (Department of Health, 2001) and The National Service Framework for children and young people (Department of Health, 2004), has set a standard on transition into adulthood. It is stated that, ‘Disabled young people need high quality, multi-agency support to allow them to have choice and control over life decisions, and to be aware of what opportunities are open to them, and the range of support they may need to access.’

Similarly to Ireland however, Hudson (2006) claims that the guidelines are noticeable for their lack of specificity and there has to be some scepticism about the extent to which the National Service Framework will radically alter transition policy and practice.

The lack of co-ordination between agencies and the minimal involvement of young people in planning their own future, are key issues that need to be addressed (Heslop et al. 2002). In an attempt to improve matters, the United Kingdom’s Governmental paper Valuing People stipulated that Directors of Social Services should ensure that
good links were in place between children’s services and adult services for people with learning disabilities.

The local Learning Disability Partnership Boards, set up by the White Paper, were to include a transition champion, while young PWID were to be a priority for health action plans and person-centred planning. At the same time, the requirement for transition planning was strengthened by the revised Code (Connexions 2001), along with the expectation that parents should be treated as partners and that young people themselves should be involved in making decisions and exercising choices. It was also hoped that the advent of Connexions, the new advice and guidance service for all 13–19-year olds in England (extended to 25 years in the case of young people with learning disabilities) would provide a full service to young people with learning disabilities by co-ordinating the delivery of appropriate supports and opportunities.

Heslop et al. (2002) indicate that previous research has shown a lack of easily accessible information to be a significant problem for parents and young people with learning disabilities at the transitional stage of life. Without information it is hard for young people and their parents to make choices about their future. Access to good information is also critical for the staff and supporters.

Since identifying the challenges above, The Department of Health (2004) has created a new role in which someone is now responsible for ensuring standards are met and have made several recommendations for the implementation of services, in order to improve the quality of transition programmes provided to PWID.
• Services should ensure that information about adult services is provided to young people approaching the age where they will make the transition from childhood to adult life in order to facilitate their involvement in decisions about service provision.

• The new role has responsibility for the arrangements to support the transition of service users between different service providers, and between children’s and adult’s services – again a task to be undertaken collaboratively with the services involved. Specific mention in this respect is made of learning disability services.

• This new role should work closely with the service to assess and meet the needs of children who are entering the transition phase from childhood to becoming adults, ensuring that adult services are sufficiently aware of the needs of children and their relationships to adults requiring services.

Hudson (2006) claims that the guidance outlined above has improved transition programmes, but highlights that additional progress is still required.

2.5.2 Transition programmes in the USA

The context of the USA may prove insightful, as the movement towards social inclusion for PWD began in the 1960’s with the Independent Living Movement. Resulting in the move towards social inclusion emerging significantly earlier in the USA than in Ireland.
In the US, transition programmes and services start in school and are mandated under the Individuals with Disabilities Education Act (IDEA), 2004. IDEA emphasises the need for specific strategies to effect successful transitions from school and mandates the Individual Education Programme, which formally establishes a survive management framework to assist young people and allows for transition planning beginning at 14 years.

Transition services under IDEA comprise a coordinated set of activities for students with disability. They promote movement from school to post school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation. (National Centre on Secondary Education and Transition 2004).

Research highlights various challenges to the implementation of the transition requirements of the IDEA Amendments that must be addressed (Johnson et al. 2002). These include:

- Greater accessibility of the mainstream curriculum.
- More development of school education planning based on students’ learning skills.
- Increased accessibility of, and full participation in, post-secondary education, employment and independent living opportunities.
- Improved support of student and family participation. This involves support of the students in the development of decision-making, communication and self-
advocacy skills and to ensure that parents are supported in the transition planning process.

- Increased inter-agency collaboration and system linkages at all levels.

Discussions regarding the right of PWID to partake in society began considerably earlier in USA than in Ireland and this has had a clear impact on transition services. As highlighted by Johnson et al. 2002 challenges still exist to these transition services and continued work needs to be done. The progress thus far however, may prove useful in an Irish context.

2.5.3 Transition programmes in Australia

Australia has disability specific anti-discrimination laws and sectarian disability laws that cover employment and a national plan of action on disability (NDA 2013). Despite this research shows that an Australian person with a disability is less likely to finish school, to have a post-school qualification, or to have a job than the general population. Legislation is not always effective, and both small businesses and government continue to discriminate against people with disabilities. Service funding operates on the assumption of less competency for people with disabilities and denies flexibility of funding for service providers and users (O'Brien et al 2002).

In response to these issues the Australian Government has been working towards a new National Disability Quality framework and National Standards for Disability Services to replace the Federal and State Disability Service Standards. The purpose of this new framework is for Governmental services to work collaboratively in order to develop and implement strategies which improve the social and economic
participation of people with disabilities in the community, and to provide access to appropriate support which best meets their needs and abilities. An agreement has been made for the need to collaborate between services during the period from school to appropriate employment and day options. In order to ensure employment and day options services, an emphasis is now being placed on state services and Government to work together towards assisting people to access the most appropriate post-school opportunities.

As Australia is on the cusp of a large transformation with regards to the services offered to PWID, beneficial learning could be taken for the Irish context, as to what progressive steps from the current setup can be made.

2.6 Conclusion

What can be concluded about the current state of programmes aimed at transitioning PWID in Ireland to options after secondary education? A paradigm shift has occurred in policies and legislation in Ireland and internationally with regards to the right of PWID to actively partake in the community and to no longer be segregated from society. It is clear that, despite this raft of legislation and policy implementations, change has progressed slowly.

The desire to meet this change has resulted in the development of service-provided programmes, aimed at transitioning PWID, in Ireland, to various options after secondary education. The limited research, available nationally and internationally, indicates a range of challenges facing these programmes. Correspondingly research
regarding both society and transition programmes, highlight a need for clearer directives regarding how the demands of new legislation and policy should be met.

The literature shows signs of the ability of transition programmes to support PWID into options after secondary education. This indication has led the author to review transition programmes in Ireland, with the aim of providing an informative piece of research for future development in line with legislation and policies.

In Chapter three the author will outline the methodological approach undertaken to carry out this particular piece of research. An explanation of the methods used to investigate the research questions will follow. A discussion of the key threats to reliability and the ethical considerations involved in undertaking this piece of research will conclude the chapter.
Chapter Three: Research Methodology

3.1 Introduction

This chapter will outline the methodology that underpins this research assignment. It will examine the suitability of this methodology and its suitability for the research question. The research assignment is interested in discovering more about the challenges that programme managers identify as relevant to the implementation of the transition programmes for PWID who are post secondary school. An approach could have been taken where by the opinions of the participants could have been gathered by distributing a survey and then these opinions could have been treated as facts and quantified into significant or non-significant findings. However the researcher is more interested in how programme providers understand these challenges and the meaning they give to them. Therefore a qualitative research paradigm has been chosen with a phenomenological approach. The priority focus is on the study of perceptions, meanings and emotions and not statistics (Mason 1996; Silverman 2005). This research assignment uses the qualitative research method of semi-structured interviews. It was hoped that using this phenomenological approach would lead to a richness of data as qualitative research is characteristically exploratory, fluid and flexible, data driven and context-sensitive (Mason 1996). There is an attempt to get inside the heads of the programme providers and make sense of their world using their frames of reference. The method selected which is most suitable for gaining an insight into interior worlds is the Semi-structured interviews which combine the flexibility of the unstructured, open-ended interview with the directionality and agenda of the survey instrument to produce focused qualitative, textual data at the factor level (LeCompte et al. 1999). The qualitative researcher typically explores the understandings, experiences and imaginings of how the research participant’s
discourses or relationships work within their social world (Silverman 2005). The phenomenological approach is considered most appropriate for this research, as the focus is to explore the personal meanings of the challenges perceived by programme providers implementing transition programmes aimed at supporting adults, with intellectual difficulties, into options after secondary education.

3.2 Sampling

Convenience and purposive sampling (Mason 1996; Silverman 2005) were the two main methods used for this research. Convenience sampling is carried out for reasons of convenience, for example, the interviewees for this research consisted of seven programme managers who were because of their geographical location in close proximity to the author. Programme managers located in Co. Dublin and Co. Wicklow. Purposive sampling chooses with a purpose to represent a location or type (Mason 1996; Silverman 2005), which in the case of this research were programmes aimed at supporting adults with intellectual disabilities after they leave secondary education in Ireland. It was hoped that as the population sample were all currently working within the field of Intellectual Disabilities that they would have up to date experiences and views in order to answer the research question.

3.3 Phenomenological approach

English and English (cited in Cohen et al. 2007) remind us that this theoretical point of view advocates the study of direct experience and taking it as face value. This means that in this research there is an understanding that each of these participants are meaning makers and that the transcripts are windows onto their consciousness, which is taken as a reality. It involves being free from all preconceptions about the world
and meeting the material in an open unbiased way. The Author is aware that there are limits to the phenomenological approach and the impossibility of being completely unbiased has to be constantly acknowledged and built into any findings or conclusions, which are reached. Also the author was aware that there was a difference in power relations between the interviewer and interviewee. The interviewees were in management positions that were in turn accountable to management above them. (Bernstein 2000 p74) reminding us of the social dimension to our lives and how one group can impose their meaning on another group who do not question this meaning, as it comes from above them. This unconscious internalisation of other peoples’ meanings which then influences behaviour and thought processes is complex. However, the author tried to counter this tendency towards socially shared meanings by actively searching through the data for dissension.

3.4 Methods

3.4.1 Data collection

As discussed, the current research assignment uses the qualitative method of semi-structured interviews in order to investigate the challenges and issues faced by programmes aimed at supporting adults with intellectual disabilities in the transition from options after secondary education (Appendix F). The researcher began by carrying out a pilot interview with a research collaborator who was put in contact with the interviewer through the National Disability Association. The interviewee was aware that their participation was part of a trial interview that was being used to fine-tune the interview layout, without actually being used as data for analysis within this research assignment. Where ambiguity arose in this interview, amendments were made. As the participants experiences are of central importance to this research
assignment, the way in which they understand and interpret the questions they are being asked is a key component. A weakness of semi-structured interviews lies partly in the fact that if the interviewers are not competent they may introduce many biases. For this reason the researcher must monitor themselves to ensure that a conflict of interest does not occur when he or she has personal, financial, professional, or political interests that are likely to undermine his or her ability to meet or fulfil his or her primary professional, ethical, or legal obligations (Resnik and Shamoo 2009). Therefore, although questions are devised from the pilot interview to act as starting points, the interviewer is prepared to manage and develop unexpected factors (Mason 1996).

Initial contact was made with potential interviewees by the programme manager of the service where the author is employed. After participants had agreed to initial contact to being made, email was then the first point of contact between the researcher and the participants. A brief outline of the research assignment was presented to each of the seven interviewees prior to any agreement to take part. An information letter (Appendix A) briefly describing the research assignment and requesting the individual’s participation was forwarded to each potential participant by email. Each email also contained a declaration of consent form (Appendix B). Once consent was given, a date, time and location was arranged to carry out the interview in full. At the start of the interview process the purpose of the interview was again outlined and any issues surrounding confidentiality were addressed, as outlined further on in this chapter.
3.4.2 Semi-structured interviews

The interviews are semi-structured in order to ensure that any additional information that may not have been pre-conceived has an opportunity to come to the fore during the interviews. Cohen, Manion and Morrison (2007) state that the semi-structured interview is a flexible tool for data collection enabling multi sensory channels to be used: verbal, non-verbal, spoken and heard. McKernan (1996) describes the interview process as one of purposely selecting individuals who possess unique or specialised knowledge or expertise in the field that the researcher is investigating. Anzul et al., (1991) argues that semi-structured interviews seek the words of the people we are studying, the richer the better, so that we can understand their situations with increasing clarity. The one to one interviews in this research assignment are enriched with all three aspects discussed by the above. The data collection involved purposive selection of experienced programme managers with the hope that they could provide their knowledge or expertise in their own words, along with acknowledgement of the importance of any non verbal nuances that were transmitted which were all possible through the use of the interview being formatted in a semi-structured manner.

Morrow (2005) stated that the more questions one asks the more answers one will get; the fewer questions one asks, the more likely one is to elicit deeper meanings from participants. For this reason each semi-structured interview in this research assignment is based on a selection of open ended questions (Appendix C) which were also designed to be provocative to the interviewee in an attempt to elicit deeper meanings from their responses. Provocative open-ended questions were used to give interviewees an opportunity to reveal their subjective frame of reference (Kadushin
and Kadushin 1997) and select the elements regarding the programmes they are involved with that they consider challenges and issues. It is also important to note that each interview questionnaire is broken into three sections.

- Section one gives an opportunity for the programme manager to describe their transition programme under some specific areas.
- Section two is formulated to stimulate participants to express their opinions of the challenges and issues facing their transition programmes.
- Section three comprises of the programme manager giving any recommendations that they might have for future transition programmes.

While the broad outline of the interview is semi-structured, all interviews are conducted in a similar manner, in which questions are asked in a particular order. The interviews ranged in duration from forty one minutes five seconds to sixty one minutes twenty five seconds, showing a mean length of fifty minutes forty seconds. On completion the interviews were transcribed in full from the recordings. This process took a total of approximately twenty-six hours. The researcher endeavoured to remove anything that could identify any of the participants by anonymising all data and removing any identifiable material such as the location of their programme. Once this was successfully completed, the researcher began to analyse the data using the technique of thematic analysis.

3.5 Data analysis

The core of qualitative analysis lies in the process of describing phenomena, classifying it, and seeing how the concepts that unfold interact (Dey 1993). The current qualitative research is being carried out by a twenty six year old male whose
background and training as a support worker is being used to guide the research, however every attempt is being made to ensure that data analysis reflects the views of each of the respondents, rather than the views of the researcher (Mason 1996 and Silverman 2005) through the use of thematic analysis.

The small scale of this research assignment suggests that a thematic approach to coding would be an appropriate starting point for analysing the data. The thematic analysis technique described by Braun and Clarke (2006) was used. The advantages of thematic analysis are that it gives a way of organising data by interpreting it into larger themes rather than focusing exclusively on grouping data by specific content type. Tesch (cited in Robson 2002) describes four basic groupings for approaching the analysis of data. The method used for this data corresponds to an approach that he describes as interested in the comprehension of the meaning of the text or action. Robson (2002) describes an editing approach and outlines the characteristics of this approach as more interpretive and flexible than quasi–statistical approaches. There are no or few a-priori codes. Instead the codes are based on the author’s interpretation of the meanings of patterns in the text.

A pilot interview was carried out by the author to ensure that the questions being used were open-ended enough to allow participants to reflect on several aspects of how the providers viewed the challenges of implementing transition programmes for post secondary school PWID. The author acknowledges that as researcher judgement is necessary to determine what a theme is, that it is possible that another individual analysing the same dataset produced by this research assignment could produce different results. Where extracts are taken from transcripts, the author is careful to
respect the sequence of the comments and to remain as faithful as possible to the feelings and intended meanings of the participants. Silences, drifting and repetitive sentences were included in the transcripts in order to try to preserve the emotional tone of the interviews. (Braun and Clarke 2006) point out the significance of paying attention to context of the interviews, which can in some cases account for contradictions in the accounts. The author was aware that he was interviewing “up”. (Silverman 2005 p215) notes; sometimes people who are holding more powerful positions than the interviewer may be unhappy about opening up or exposing problems or difficulties within their work practice.

The coding of the semi-structured interviews involves a six-stage process derived from the thematic analysis model advocated by Braun and Clarke (2006). During the early phases of analysis, the author was required to engage in open coding, which is an analytic process through which data are examined line-by-line to identify provisional concepts. Inductive analysis is used during this phase as a means to code the data without trying to fit it into a priori categories, or the author’s analytic preconceptions (Braun and Clarke, 2006). A vast number of codes initially emerged from the dataset (Appendix D). Due to their vastness, after the initial codes were created, the author chose to further refine them by including only those codes that are recurring (Appendix E) in order to condense the data into units or segments that were easier to manage (Blaxter et al. 2001). Once the final set of codes was compiled the author was better able to begin the process of theme identification by sorting the remaining codes into potential themes. The process of re-reading the codes and the texts was undertaken in order to refocus the analysis at the broader levels of over arching themes based on their similarities and differences. This was in some ways the
most interesting if most difficult aspect of the coding. Responding to surprises or interesting points in the transcripts required a continuous interrogation of the meaning of the texts and their relationship with each other. One of the important strategies which helped to stay on track and out of Schon’s swampy lowlands was the reminder to keep asking the question why is this being coded and what will it bring to the research document (1995). At times the process became tedious and it helped to review what had been gathered in a category to see if it appeared to have multiple dimensions and what did this mean in relation to the project. Therefore there was an on-going interplay between the coding particular texts and eliciting their connection with the rest of the data.

3.6 Coder reliability

Coder reliability is a difficult concept. How to ensure that a code was being used in a consistent way was one of the questions that needed to be addressed. As the coding happened over a six-week period there wasn’t too much concern about whether the codes would be used the same way over time. The interpretive coding is more likely to be inconsistent than descriptive coding (Silverman 2010). Therefore a colleague coded a duplicate of the same document and a collaborative discussion took place about what categories were used by one and not by the other. In most cases there was compatibility and any differences could be explained in differences in how concepts were labelled rather than differences about what the concepts meant. The colleague came from a similar educational and research training background, which meant there was a shared conceptual background. If the colleague had come from a different discipline this may have generated more differences for discussion and highlighted the situated nature of the learning.
3.7 Ethical considerations

Ethical issues in qualitative research are often less visible and more subtle than issues in survey or experiential research (Morse 1994). A subtle and often overlooked aspect of the consent process is the probability of participants ‘forgetting’ they are being observed and/or recorded once they have become made to feel at ease by the researcher whose intention is to aid the participant to relax so as to gain access to their ‘real story’ Cassell 1980 (cited by Morse 1994). At all times throughout this research assignment ethical issues of this sort amongst others remained at the forefront of the researchers mind. All participants were assured of confidentiality before taking part in the study by being provided with an information sheet and consent form prior to their taking part in the study, as mentioned previously. In order to protect the identity of the participant’s anonymity has been provided by the changing of participants’ names, which in all cases were chosen by the participants themselves. The researcher has also removed any identifiers (e.g. service name, place names or the use of other people’s names). All participants were given the researcher’s full contact details and made aware, through face to face discussion and the consent form, that they can withdraw from this study should they choose to at any point up until and before August 29th 2014. This ensures that the participants are giving informed consent at the time of the interview and also that they are given sufficient time to reflect afterwards on their having taken part in the research assignment. As all the participants were programme managers currently managing transition programmes it was imperative to the researcher that no harm was done the programmes under review or the services providing the programmes during the interview stage of the study. For this reason participants were informed that they could stop at any time during the interview stage if they were uncomfortable with any of the questions and did not wish to continue.
Each participant was sent a copy of the finalised transcript in addition to the findings and discussions chapter to ensure validity of the research assignment. Each participant was also offered the opportunity of receiving an electronic copy of the final thesis, upon its completion. It should also be noted that the School of Social Work and Social Policy Research Ethics Approval Committee reviewed the research proposal for this research assignment in May of 2014 and granted permission for the research assignment to be undertaken.

Once all ethical considerations were taken into account, the interviews were conducted and the style of data analysis was chosen the process of searching across the dataset to find repeated patterns of meanings and challenge the perceived wisdom which the researcher located in previous research in relation to programme managers could commence.

3.8 Limitations of the research approach

1. As the data gathering is being conducted with programme managers of services, an issue arises with regards to the fact that they are custodians of the programmes being researched. The author must be aware of sensitivities surrounding the presentation of challenges within the programme in case the interviewee’s feel they appear as a criticism of the programme. To counteract this, the author has assured anonymity of all data gathered throughout the interview process.

2. The author acknowledges that only speaking to one stakeholder, results in the fact that a variety of stakeholder’s opinions and experiences are not being
taken into account. Due to the timeframe and small-scale nature of the research assignment it is beyond the scope to extend this data gathering to a greater variety of stakeholders due to the complexity of ethical issues it would generate. The author is aiming to provide a quantity of rich data within the confines and highlights the need for further research to be conducted on the area in future.

3. As there is only one perspective used to generate data, the author acknowledges the threats to validity that exists. The author attempted to counter these threats to validity by using the techniques of member checking and negative case analysis.

- Member checking requires all transcripts and interpretations of transcripts to be returned to interviewees in order to guard against researcher bias. (Robson 2002 p175)
- Negative case analysis is the process of countering any theories that the researcher has developed whilst analysing qualitative data by searching for instances within the data set that will disconfirm your theory. This is also known as ‘playing devil’s advocate’ (Robson 2002 p175)

3.9 Conclusion

This chapter considered the research design for this small-scale piece of research. The rationale for the research methodology was outlined and the method used to conduct it was discussed. The chapter continued by highlighting the means of ensuring validity and rigour were present throughout and concludes with an overview of the limitations
of the research methodology. Chapter four will present the findings from the method chosen to answer the research question.
Chapter Four: Findings

4.1 Introduction

The purpose of this research is to gather evidence from the perspective of programme managers from disability services who oversee the design and implementation of programmes aimed at supporting PWID’s transition into options after secondary education in Ireland. The following research question was addressed:

‘What issues and challenges are facing programmes in Ireland developed to support adults with intellectual disabilities transitioning into options after secondary education, and what issues should be considered during the future development of these programmes?’

This chapter involves a presentation of analyses of the data. A thematic analysis approach was used with the qualitative data to identify commonalities from the interviews conducted with seven research interviewees.

The analyses are divided into three sections and from these sections a number of sub-sections emerge from the thematic analysis, as outlined below:

Table 4.1: Challenges and Subthemes within the data

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Contributing Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complying with legislation and policy</td>
<td>Social inclusion for PWID</td>
</tr>
<tr>
<td></td>
<td>Getting families on-board</td>
</tr>
<tr>
<td>Providing an educational programme within a disability service</td>
<td>Transforming practices of disability services</td>
</tr>
<tr>
<td></td>
<td>Providing FETAC accreditation</td>
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<td></td>
<td>Lack of collaboration</td>
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<tr>
<td>Progression after the transition programmes conclude</td>
<td>Locating responsibility for lack of progression</td>
</tr>
<tr>
<td></td>
<td>Lack of appropriate forward planning</td>
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</tbody>
</table>
4.2 Research interviewees

The interviewees involved in the research, were a selection of programme managers responsible for the ‘overall guidance and leadership within services’ (Brown 2007). Disability services in Ireland generally have a management structure, which features front-line staff reporting to managers who in turn report to programme managers.

As mentioned previously, in order to preserve anonymity, the interviewees were all given the opportunity to provide an alternative one letter-name to represent them in this study, none of which pertain to the interviewees’ actual names. Outlined below is some basic information regarding the interviewees and the programmes that they are programme manager for, within their service:

Table 4.2: Overview of Interviewee and Programme Data

<table>
<thead>
<tr>
<th>Participant</th>
<th>Type of service provider</th>
<th>Supports offered to service</th>
<th>Location of service: Urban/Rural</th>
<th>Transition Programme delivered within service or externally</th>
<th>Hours of programme (per week)</th>
<th>Gender mix of participants</th>
<th>Duration of programme</th>
<th>Funding provider for programme</th>
<th>Tutors/staff provided internally or externally</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Intellectual disability and Mental Health Supports</td>
<td>Day services</td>
<td>Urban</td>
<td>Externally</td>
<td>15-35</td>
<td>Even</td>
<td>Three year programme</td>
<td>HSE</td>
<td>Internally</td>
</tr>
<tr>
<td>C</td>
<td>Intellectual disability</td>
<td>Residential and Day services</td>
<td>Urban</td>
<td>Within service</td>
<td>30</td>
<td>Even</td>
<td>Dependent on needs of individual participants</td>
<td>HSE</td>
<td>Internally</td>
</tr>
<tr>
<td>E</td>
<td>Intellectual disability</td>
<td>Residential and Day services</td>
<td>Urban</td>
<td>Mixture</td>
<td>35</td>
<td>Even</td>
<td>Four year programme</td>
<td>HSE</td>
<td>Mixture</td>
</tr>
<tr>
<td>H</td>
<td>Intellectual disability and Mental Health Supports</td>
<td>Residential and Day services</td>
<td>Urban</td>
<td>Mixture</td>
<td>32</td>
<td>Even</td>
<td>Two year programme</td>
<td>HSE</td>
<td>Mixture</td>
</tr>
<tr>
<td>M</td>
<td>Intellectual disability and physical disabilities</td>
<td>Day services</td>
<td>Urban</td>
<td>Mixture</td>
<td>35</td>
<td>Even</td>
<td>Two year programme</td>
<td>HSE and Genio funded</td>
<td>Mixture</td>
</tr>
<tr>
<td>N</td>
<td>Intellectual disability</td>
<td>Day services</td>
<td>Urban</td>
<td>Mixture</td>
<td>32</td>
<td>Even</td>
<td>Two year programme</td>
<td>HSE and Genio funded</td>
<td>Mixture</td>
</tr>
<tr>
<td>R</td>
<td>Intellectual disability</td>
<td>Day services</td>
<td>Urban</td>
<td>Mixture</td>
<td>32</td>
<td>Even</td>
<td>Dependent on needs of individual participants, Maximum of three years</td>
<td>HSE</td>
<td>Mixture</td>
</tr>
</tbody>
</table>
4.3 Findings

A new form of support required for the first time within disability services in Ireland is to plan and provide an educational programme to support the transition of PWID into options after secondary education. The challenges faced in achieving this objective, according to programme managers of seven of these services are outlined below.

4.3.1 Complying with legislation and policy

New legislation and policies nationally and internationally have been driving change from the traditional care-based form of support to a more independent-driven support for PWID in Ireland. A theme emerged with regards to the challenge of ensuring that these transition-based programmes comply with new directives from legislation and policy documents. Six interviewees focused on New Directions or HIQA standards specifically.

Six people commented on different challenges presented by the introduction of this new policy and legislation.

N: New Directions, it’s a big challenge for the organisation, it’s a big challenge for families to hear that their son or daughter are no longer going to be coming to the same building are going to be based in different localities and moving around a lot more, it’s a big issue for staff who have come to the same building for years, to do the same sort of work, quite frankly it’s a big issue for the building.

H: It certainly is [a challenge] and it’s not a challenge that we actually think is the right challenge in many respects. We are very committed to the new requirements of New Directions.

R: I think everyone’s trying to […] mmm, you know it’s like a panic button gets hit and you have to, you have to be at that standard all of a sudden.
C: I think it will be challenging, it will be a change for them [PWID], it will be daunting, will be worrying. And there is concern that people won’t be stimulated as continuously as they are in a day service. That they could eventually become bored.

M: Yeah the staff will say there is a bit of paperwork to be filled out, yeah all staff would say, ah, and planning.

E: It’s just I think you know the whole graduation of thinking around this stuff, that the training place can be positive. Like the rest of us we learn by doing. But it’s not at all easy.

The six interviewees quoted above are in agreement that a challenge has arisen as a result of attempting to meet this legislation and policy for programmes for PWID. This change has brought a shift in how programmes are run and regulated. Interviewees discussed the challenges with a variety of different emphasis, two interviewees emphasised the negative implications connected to the challenge of dealing with regulations. Three interviewees mentioned stress, panic and worry with regards to these challenges. The overall sense from these six interviewees is that a struggle exists in meeting these new legislations and directives.

Throughout these discussions three sub-themes emerged in relation to what the barriers to implementing programmes that meet new legislation and policies are, from the point of view of the programme managers. The sub-themes are: resources, society and family concerns. These are investigated in further detail below.

4.3.1.1 Resources

A majority of the interviewees identified issues with funding as an obstacle to being able to implement the directives of the new legislation. These perceptions were that services would face a dilemma in implementing these directives unless an increase in
funding is provided. According to the interviewee’s, as new demands were being made of the service a corresponding increase in funding was required to meet these demands. Interviewees H, R and A are very clear that funding is the principle challenge to meeting these new demands.

H: And I think the new standards, set standard qualities, as standard benchmarks that we should be achieving but it is, it’s a bit nebulous at the moment […] we don’t quite know if there is additional funding going to be made available to meet those standards.

H: younger families come with the expectation that this is what it’s going to be [in line with new legislation and policies], particularly for the 15-18 year olds and the system just can’t cope with that immediate change […].

R: So, that funding for me should be driven by the person or the group. But our funding comes in and like I said already we have to apply it. It appeared that the legislation made demands on the programmes which could only be met by an increase in resources.

A: Money is taken away from us, and I think when we are being seen to be able to do it, money is cut back a little bit more.

Whilst interviewee C is in agreement that meeting the new standards is principally a matter of funding, they elude to the service being in favour of this change, but being limited in their ability to respond to it until new funding is allocated to the service.

C: Yeah so I suppose the resources are drying up, we have HIQA coming in and we have our funding reduced and when you know we have to comply with regulations that HIQA want us to, which you know is great, it’s amazing it’s really good and it’s very service user focused but it costs money.

Despite the large discourse regarding funding, it is interesting that only one of the seven interviewees discussed the economic downturn in Ireland and the subsequent cutbacks as an issue in running their services.

H: our funding has been significantly hit over the last five years, that means people’s salaries have gone down, people’s jobs have been lost,
a whole range of different measures [...] And that challenges the quality of what we do and I think the new standards, set standard qualities, as standard benchmarks that we should be achieving.

One interviewee dissented from the view that funding is a key challenge in meeting the directives for the new legislation and policies required. Interviewee N suggested that in the years following the economic downturn, a realisation came in society that money is not a challenge to meeting the directives. Interviewee N provided the opinion that becoming more ‘community-focused’ is the key in achieving a programme for PWID, which meets the new directives.

N: Society began to look at itself again. And even though there was no money, they [disability services] saw that actually it’s not about money but when people actually started looking within themselves and said you know what this is about becoming more community focused.

Six of the interviewees discussed how increased funding was a dominant obstacle to implementing this legislation in their programmes. The dominant perception was that the immediate concern for programme managers in meeting new directives and standards such as New Directions is with accessing an increase in funding. However interviewee N challenges this view and insists that there is a need for programmes to become more ‘community focused’ in order to comply with the new policies and legislations driving change.

Only one interviewee discussed a lack of reference to the impact of the recession, on the services. This makes it difficult to interpret and draw any conclusions from. This could be explained either as a lack of cutbacks to the funding of the services or that the need for an increase in funding is accentuated by this recession. Either way a theme emerged from programme managers that in order to improve the quality of the
programmes as required by the new legislation and policy, that an increase in funding is needed.

4.3.1.2 Social inclusion for PWID

As identified in the Literature Review, a priority of new legislation and policies for programmes is to ensure that PWID are given equal opportunity to be included in society, as is the case with the rest of the population. Each of the interviewees acknowledged that this was a new but important aim of the programmes that they offer. Key discussions arose during the interviews with regards to the challenge that this presented within Irish society;

H: [...] what is going on internationally from Ireland to Canada, Australia, New Zealand, all of these places where it’s very obvious that there is plenty of evidence that there should be an expectation [that PWID should be integrated into society] as a citizen with their rights being fulfilled [...] until that becomes a greater voice then we are not going to see massive change.

A: I think it’s very much, it’s archaic and there’s a lot of people that need to be, eh, I suppose enlightened of the community access, the community provision.

E: It still means that the community have a low expectation for them [PWID...] society as a general, people are generally thinking the child mentality for people with I.D.

C: Em, as opposed to being considered a viable employee as worthwhile as anyone else in there, for full wage. I think the disability will always drive what comes next.

R: There is no one assigned in our government that is a person that represents people with disabilities, so how could we possibly have a society that can know what’s needed, or how to address them.
It appears that there is substantial agreement among all interviewees that meeting the expectations of the legislation and policy requirements of having PWID socially included requires a shift in how society views PWID. Interviewees focus on the need for a change in society to occur, before the programmes that they are responsible for can meet these new directives set out by the new policies and legislation. Interviewees A, H and R further develop this view.

A: But I don’t know if the mind-set of New Directions has sunk in to mainstream society. I think it’s still very, it needs to come from other places other than service providers.

H: […] there is a societal shift required from being centre based to being what might now happen, being community based or being further embedded in the community.

R: Em, there seems to be still in society this idea that, ah sure they don’t want that. They wouldn’t want to have that job, or sure how could they do this. So there is still a society thing.

An undisputed theme emerged from the interviews of the lack of readiness of Irish society to meet standards and legislation and the impact that this has on transition programmes for PWID into options after secondary education.

4.3.1.3 Getting families on-board

All of the interviewees referred to the implications for the families of PWID partaking on programmes, which are attempting to meet the directives of new legislation and policies. The directives promote a more person-centric approach to programmes for PWID that should be based in the community and focus on encouraging the independence of the PWID. According to six of the interviewees, adapting to this change has been a challenge for families. Interviewees E, C and A highlight the
challenges faced when adapting to the change of moving from the old form of support towards this new approach.

E: [...] it’s a big challenge for families to hear that their son or daughter are no longer going to be coming to the same building are going to be based in different localities and moving around a lot more [...] 

C: That was difficult in the first couple of years for families to get their heads around. Eh, that the babysitting service would be gone.

A: [...] that’s very difficult for parents and for the person themselves. You know that person’s expectations are as what their parents is. You know, Monday to Friday 9 to 3 or whatever.

R, and N discuss families struggling with change also, however, it is relating to the change from the education system to life after school for PWID.

R: So from a family perspective, there is a fear; my son’s left school, what happens now? They’re not going to college, they’re probably not getting a job straight away. … I’m not sure how many of them know about it. But it’s; they’re providing it, there’s funding there, lets get them in. And I understand that to be honest, I really do. I understand that families feel that way because they want their child to be progressing, and also there’s the fear of the burden of having them at home every day.

N: I think one challenge, can be around families, can be in the sense around families, moving in a sense to the first non-school programme, families do find that a bit of a struggle particularly around safety.

Interviewees M and E refer to the challenge for programmes of getting families to support the changes that the new directives bring.

M: I suppose you have to have the family buy in as well. Which is not always easy […]

E: Some families would be strong saying I want him to go with Mary, Tom and Jim to (centre) with his friends, so that potentially can be challenging, if he lives in (location) or (location) and we would be thinking oh you know what, for all other positives in terms of his own
community, getting to work, people knowing him or her in their own community they would be better off but some families go with that, some kick and scream, so you have to go with it.

The seven interviewees agree that families are facing a big change in adapting to these new programmes which require PWID to be more independent and based in the community, rather than the traditional centre-based service. Interviewees identify this challenge as crucial to the successful implementation of programmes, due to the important roles that families have in the lives of PWID.

The interviews highlight, that to understand the implications of the new directives issued by the most recent legislation and policies, the role of resources and families need consideration.

4.3.2 Providing an educational programme within a disability service

A theme emerged with regards to the challenges facing disability services, when providing transition programmes supporting PWID into options after secondary education. Programme managers noted that services are now required to change traditional practices and adapt to more education-based service provisions. Throughout the interviews, consensus emerged with regards to challenges facing programmes as a result of developing educational programmes within a disability service.

4.3.2.1 Transforming practices of disability services

The development and implementation of programmes aimed at supporting PWID into options after secondary education, has placed an emphasis on updating practices
within services. Meeting the aims of programmes which are individualised, person centred and community-based, has resulted in a variety of challenges according to interviewees. These programmes require a transformation from care-based support to a form of support, which focuses on educational attainment for PWID. Interviewees referred to the challenges of incorporating this change within their service as challenging on a number of levels. Interviewees N and H, mention the struggle for staff members to adapt to changing work environments:

N: […] it’s a big issue for staff who have come to the same building for years, to do the same sort of work, quite frankly it’s a big issue for the building […]

H: That’s gone because now they are supporting in some cases, without an office, you know, without a fixed place to work but they’re supporting, maybe three or four people in an educational setting which is really an educational setting, as opposed to being in a campus, a segregated setting for people with disabilities. So that cultural mind shift of, okay I’m no longer fixed, I’m not necessarily 9 to 5, I’m not necessarily in one place, has been a very significant shift for some staff […]

Five interviewees discussed the need for an updating of practices within their service, for both staff and PWID, if true learner-centred education programmes are to be offered:

R: […] but we developed a drop-in club just as the downturn came, in line with the new legislation. Now there is forty people attend there, so it’s not a drop-in anymore now it’s reversed back to the old system where they spend too much time hanging about, they got use to the old ways.

H: Allowing time for it to happen, yeah. The challenge for organisations like us is, number one enabling it and not being resistant to it, because we could kill it by saying none of our people are going to any of these places and we could just retain.
M: […] we were lucky in that the staff members we got were young as well as they were in the [New Directions] mind-set and it wouldn’t have worked as well if you put a 45 year old in there.

A: [Because] you’re a disability service your expectations [for PWID] is probably a little bit lower than if you were just a mainstream educational provider.

Interviewees R and E refer to a particular need to update the ethos or the culture of the organisation that they are involved in:

R: Em, ethos within the organisation. I suppose you mention time, you know people are under pressure, there’s a big client group here, up to around 220 as well our learning groups of maybe 10. Sometimes the 10 get lost in the bigger demands of the service.

E: There is a cultural shift required here from being centre [or disability service] based to being community based or being further embedded in the community.

The challenge for services of adapting to educational programmes, which encourage a transformation in line with new legislations and policy, emerged as a key point for interviewees. Within the mixture of challenges and implications, a need to identify a means of promoting this transformation to all stakeholders, materialised as a crucial development. Further practical challenges were discussed, including the provision of accreditation.

4.3.2.2 Providing FETAC accreditation

Interviewees discussed the expectancy of PWID, on programmes aimed at supporting the transition into options after secondary education, to receive FETAC accreditation as a challenge. According to interviewees, PWID were expected to gain FETAC accreditation, as a result of partaking on a transition programme. This was seen as being at variance with the achievement of real life skills that PWID could apply in
real life situations. Interviewees R, A and H questioned the relevance of this qualification to PWID:

R: […] whilst a disability service is leading the [FETAC accredited] programme, I don’t think our programmes will ever help their students to meet the demands of real life, real standard, that is required for someone to meet what the world is asking for right now […] Are they leaving here with a skill? No, but they may achieve a certificate.

A: We look deeper into what the individual wants to achieve their goals, their dreams and we set our programmes around achieving that with the individual. Linked where we can, and eh, where appropriate to an academic accreditation like a FETAC level but not specifically and not primarily, so we’re looking at what the individual wants to achieve.

H: […] I don’t think quite relevant for a lot of our people, which is have they obtained the level of certification that people have aimed for? That’s obviously one measure. Umm, for a lot of the stuff we do which is about life skills, generating a degree of independence for the individual.

Interviewee E suggested that FETAC accreditation standards were pitched too high for what the PWID on their transition programmes were capable for:

E: And you will probably have only about 40 people out of about 300 able to get accredited in something, every year, like it’s low.

A noticeable feature of this finding is the questioning of the relevance of FETAC accreditation for two reasons; according to interviewees it may be pursued at the expense of creating valuable real life learning experiences, or, it may not be suitable for PWID as the levels are unobtainable. However, it cannot be concluded that FETAC accreditation on programmes is irrelevant. Interviewees certainly discussed the need to review how it is pitched and delivered at present.
4.3.2.3 Lack of collaboration

From the perspective of benefiting the transition programmes being offered to PWID, interviewees discussed the positive implications of working alongside other disability services, offering programmes with the same aims. As the programmes are a new development in Ireland, interviewees identified a distinct lack of collaboration with other agencies offering transition programmes:

M: I’d have to admit that we are a little inward looking sometimes [with our programmes], we really should prioritise working more with other agencies more.

A: From a service perspective we have no dealings with other services.

N: […] in terms of running our programme or working on next steps, we’d to the best of my knowledge no we don’t link to external organisations. I think this is a crucial element that we are eh, lacking.

C: You can find plenty of community based programmes, in a centre or a big disability provider like (Disability Organisation) for example, they have been doing it for years and doing it quite well but not in a community based way, and we are still seeking partners who are doing it more, our way.

H: […] citizens who have a right to this type of education and we have to find ways of enabling that to occur and that’s there, in terms of the ether, everybody sees that as a requirement but I don’t see any partnerships on it, just yet.

Given that services are being asked to change traditional practices and develop new approaches, there is recognition by a majority of interviewees that partnerships could help to develop new community based practice but this is not happening. The data does not provide any evidence of why these partnerships are not happening.

In addition to seeking collaboration from other services, five interviewees identified that new standards in implementing transition programmes demanded that the
families became a stakeholder in the implementation of transition programmes along with the services and the PWID themselves. The interviewees recognised the presence of fear experienced by families as a barrier to this partnership. Fear was discussed in terms of the families’ uncertainty about the changes that the new community based model would bring to the lives of the PWID:

N: It’s a big challenge for families to hear that their son or daughter are no longer going to be coming to the same building […]

R: So from a family perspective, there is a fear; my son’s left school, what happens now? They’re not going to college, they’re probably not getting a job straight away. […] I’m not sure how many of them know about it. But it’s; they’re providing it, there’s funding there, let’s get them in. And I understand that to be honest, I really do. I understand that families feel that way because they want their child to be progressing, and also there’s the fear of the burden of having them at home every day.

A: You can it straight away, almost a desperation to get a place for their son, daughter and for that place to be lifelong. It’s not easy adapting but we have to try and help them along the way.

C: And getting to buy in is hard for older families, you know? They think you are changing what we were happy with and expecting us to go along now with this new plan.

E: You can go ahead in-house and do anything but you are at nothing without family. Some of them are fearful of what might happen, risks, dangers.

Despite this, two interviewees highlighted that if families consider this more partnership based-approach a positive development may occur, which may be beneficial to the participant on a programme.

E: So whatever we need to do, we need to get families on board to see and the communication for that family in that year is crucial. Then it can be wonderful from then on.
M: Family involvement is absolutely imperative, if you haven’t got family involvement. Yeah and families who want the best for their kids, you have to have the buy in.

The findings in this theme outlined three main challenges in providing an educational programme within a disability service. The implementation of programmes aimed at supporting PWID into options after secondary education has had an impact on services and it is clear that further development is necessary to promote this transformation. This will be discussed in more depth in chapter five.

4.3.3 Progression after the transition programmes conclude

An expected outcome of supported transition programmes is that PWID will progress to an appropriate community-based next step in education or employment.

Appropriate progressions of PWID partaking in programmes was recognised as a challenge in each of the seven interviews. The seven interviewees acknowledge that currently, PWID have achieved very limited progression, into options after secondary education, following their completion of programmes. Four of the interviewees stated openly that progression does not exist after programmes are completed:

M: And that is unfortunately what happens next. There is no provision out there. For these young people, the only thing they can look forward to [is] a day service […] and then you say what is next for them? Nothing. Sitting inside watching television. I mean, my God. Can you imagine? It must be awful for them.

R: A lot of people are disappointed at the end cause they’re not chefs. They’re not getting jobs in hotels. Opportunities just don’t exist.

N: Obviously I think work is hard to find for [PWID].

H: Now breaking that down is the hard part for us and for them, it creates difficulty for some of the individuals we support in that they are seeing their old friends go off and have these kinds of opportunities and we’re saying well why can’t I do that […]
A consensus appeared that progression options are limited. The most noticeable aspect of these findings is that no one was positive with regards to progression options for PWID after completing these transition programmes. Interviewees were more open with regards to locating possible reasons for progression not happening.

4.3.3.1 Locating responsibility for lack of progression

There was a limited attempt by two interviewees to attribute some responsibility for this lack of progression to the training programmes, while five interviewees attributed societies’ response to PWID as a reason for the lack of progression options. In combination with these elements interviewees highlighted resourcing as a factor in the lack of acquiring appropriate transitions upon completion of programmes for PWID.

R and E both indicated that the programmes might have responsibility concerning the lack of PWID transitioning into desired options after programmes conclude:

R: One of the big problems for me, and it’s what I touched on earlier, is; where people are going next, isn’t necessarily based on what they did in their course and wanted to do afterwards.

E: So if look at statistics and success on an organisation we’re doing great, everyone has moved on, but have they had some sort of outcome where they’re as close to my life and your life as they could be? I would doubt majorly to be honest.

Five interviewees identified a lack of preparation within Irish society as a reason for the lack of progression of PWID, appropriate options after secondary education. Interviewee N discusses a lack of preparation with regards to employment options:
N: [...] not being, warned is the word that came to my head. I don’t know if that sounds right or not but you know suddenly they’re going to have all these people on they’re doorstep that they thought were being looked after somewhere and we’re saying well no they’ve to be with you now. And as I say there’s no preparation or training or information or they might not know what epilepsy is. You know suddenly they’ve got a work colleague that might fall down in front of them, they don’t know what it is, that’s, that’s a challenge.

The following quotes from A, H, E and R discuss transitioning into further education after programmes are completed. A lack of readiness on behalf of educational settings is attributed as reasoning for PWID not transitioning after programmes are completed.

A: The actual teaching course, the universities themselves or the I.T.s or the third level education organisations eh, at a management level buy into the process, but it hasn’t filtered down to the teaching staff.

H: What we are finding is that people are going into classes and are being left or are being asked to leave because they are being disruptive because they may have outbursts for whatever reason, which is part of their disability and none of that is taken into account when considering how they might operate within a classroom.

E: I think if there is a FETAC level 3 in the community then why not take it up, but [PWID] may not have the skills.

R: You know, you try to integrate someone into a class, and they might say, well we don’t have the resources here to have that person in this class. Or; I don’t know how to work with someone with a disability.

Furthermore, interviewees E, M and H discuss the negative impact that families may have on the transition into options after secondary education for PWID:

E: [...] we would be thinking oh you know what, for all other positives in terms of his own community, getting to work, people knowing him or her in their own community they would be better off but some families go with that, some kick and scream.

M: We get people that don’t want to work for various reasons; overindulged some and then others their family never worked so it’s just alien to them.
H: And I think that’s when some families, not all, but some families will have to wake up and get on board with what’s required.

There is a general agreement that there are limited progressions available to PWID at the end of transition programmes. A number of reasons are provided for the lack of progression, interviewees R and E begin to explain this in terms of the responsibility of the transition programmes and five of the interviewees share an understanding regarding society’s lack of readiness to include PWID, as a barrier to progression. Finally three interviewees highlight the negative consequences of families who may have a discouraging effect on a PWID’s transition after service-provided programmes conclude.

4.3.3.2 Lack of appropriate forward planning

In terms of the successful progression of PWID into options after transition programmes conclude, interviewees discussed a lack of forward planning as an issue, which may have a negative impact. In line with literature highlighting best practice for PWID’s transitioning into adulthood, interviewees determined that collaborative, person-centred, forward planning was an essential element of achieving successful transitions. A lack of finances and staffing-issues within services were discussed by programme managers again, as a cause of this lack of planning:

M: Because you are stuck in the day-to-day, what happens is the day-to-day always trumps the thing in the future. You have to deal with the thing that’s happening now, but look into the future, particularly when the future is five years down the road […]

C: I’m focusing on challenges now but the challenge then must be having, [correction] putting the staff time out and planning to go so far back, it’s tricky enough day-to-day keeping on top of things, but when you are planning ten years ahead […]

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H: These are citizens who have a right to this type of education and employment we have to find ways of enabling that to occur and that’s there, in terms of the ether, everybody sees that as a requirement but I don’t see any investment going into it, just yet.

M: Funding and getting the right staff. They are the big challenges to forward planning.

The interviewees M and C talk about an attempt within services to plan progress for PWID into options after programmes conclude. All four interviewees identify that funding and staffing issues are a barrier to this happening. Additional concerns raised by interviewees, surround the lack of information available to the community regarding transitions for PWID after programmes complete:

E: We rarely get that from the individual themselves emmm, because they don’t have enough information they don’t have the same awareness of what is out there.

C: The family really needs more information, they need more education about the future because they feel they have battled their way through the childhood stages with the individual and very quickly they now have an adult and they want security, they want to know that the person will be safe and the person will have a future that will be looked after by the state and particularly by the organisation whoever they are, they will want to know there will be security for the person.

Interviewees R and M develop this theme by discussing the fear that accompanies this lack of knowledge of available options:

R: We can look at all the challenges when it comes to our guys; fear, you know am I good enough to be in a college with anyone else, am I safe, will my DA get lost, if I’m in there will they say oh you don’t need D.A. Em, all those fears need to be addressed quite regularly.

M: Em, so people, the more we go in to the community, people worry about where funding is, will my child still be receiving this, will you still be helping them.
It is clear that the selected interviewees feel that challenges to progression exist within their service and a pattern emerges of interviewees feeling that these challenges are being faced independently by their service. The call for working collaboratively with external organisations is only alluded to by two interviewees, however:

R: If we can inform people, in the workplace that someone is coming, a person with a mild intellectual disability, it changes it. It makes it more accessible. But there seems to be this thing of; let’s not say anything because that’s not inclusive. Uhm, and that’s not really helping anyone.

M: And planning. There’s probably never enough time allocated for it but we should prioritise working more with other agencies on it.

A lack of appropriate planning with regards to PWID progressing into options after transition programmes conclude in their service is a matter of concern for the majority of interviewees in this study. Programme managers propose a variety of reasons, however it is clear that this is a matter requiring further investigation.

4.4 Conclusion

The purpose of this chapter is to present and analyse the findings of the data collected from the qualitative method employed in the research assignment. Discussion of these findings, their potential impact on informing the future of transition programmes aimed at supporting PWID into options after secondary education are the focus of the following chapter.
Chapter Five: Discussion

5.1 Introduction

The following chapter will discuss the significance of the findings in relation to the research questions and where appropriate establish links between the findings and the wider field of enquiry identified in the literature review.

Evans, Gruba and Zobel emphasise the importance of critically examining your findings in the light of the previous state of the subject as outlined in the background, and make judgments as to what has been learnt in your work. (2011 p162)

Before attempting to achieve this, a review of the research question may prove valuable in order to provide a context for the chapter.

“What issues and challenges are facing programmes in Ireland developed to support adults with intellectual disabilities transitioning into options after secondary education?”

The author will discuss the findings within the context of the overarching themes and subthemes that emerged and deepened the understanding of the challenge. The chapter will end with remarks on how the findings relate to the research question along with providing a variety of reflections on the outcomes of the research and recommendations for future research.

5.2 Current state of transition programmes

This discussion will start by exploring the range of views expressed by this sample group of disability service programme managers and the understanding they had of
the challenges facing programmes aimed at transitioning PWID from secondary education to options after secondary education, within their service. Whilst the research is focused on challenges and issues, the first overarching theme that emerged from the transcripts was the consensus of interviewees that supported transitioning has an important role to play in best meeting the needs of a proportion of PWID during the challenging period after secondary education, as discussed within research (Van Naarden et al. 2006; May 2001).

The desire to support PWID during this transition into ‘adulthood’ appears to have led to the creation of these transition programmes, however it is clear from the findings that programmes are offered autonomously by services. This would be in line with the research conducted by The National Employment and Vocational Training Agency and the National Disability Authority (FÁS, 2006; NDA, 2004). A majority of interviewees alluded to external reasons, such as finances and staffing, as to why the programmes may not always be meeting the needs of PWID, however only interviewees E and R felt that their service-provided programme might have a responsibility with regards to improvement of the programmes.

In accordance with the available research, services may require an increase in collaboration with other organisations and a new approach to the provision of support (Heslop et al. 2002), if programmes are to successfully meet the demands of PWID transitioning into options after secondary education. While the aims of successful transitions programmes, are clear to interviewees, it is evident that services require additional support in understanding how to comply with changing demands.
5.3 Impact of legislation and policies

The challenge for programmes to be compliant with new legislation and policies directing the provision of programmes for PWID was widely discussed throughout the interview process. Dimensions of this theme emerged, including barriers to compliancy as a result of resourcing issues and family expectations. Together these themes give us a window of the impact this legislation is having on the day-to-day experience of running these programmes.

From the literature review we can see that since 2005 there has been a variety of key new policies and legislation created in Ireland and internationally which have proposed a paradigm shift in society’s view of PWID (New Directions 2012, UNCRPD 2007 and Disability Act 2005). Each of these documents required a change within disability services in order to comply with the changing landscape of disability. Whilst interviewees spoke of the benefits of new legislation and policies guiding the programmes, only two interviewees spoke with confidence of how their service was meeting new directives. A lack of clarity in relation to meeting these guidelines was evident in the findings, as interviewee H said: *there are* set standard qualities, *as standard benchmarks that we should be achieving but it is, it’s a bit nebulous at the moment.*

From the literature review (O’Brien et al. 2011) we see that a significant shift is required for services to comply with these new directives. The move from centre-based supports to community-based supports is essentially about changing the model from a dependency approach to a more independent approach. Within this theme a supporting discussion emerged about the role of the family. The theme suggested that
families needed to be willing to join as partners into this new service model. It
demanded that stakeholders, namely the PWID, the programme providers and the
families needed to share a vision of PWID demonstrating more agency in their life.
This could not be guaranteed by an increase in funding. Despite this and for the
second time in the findings, shortages of resources were also identified as an obstacle
by a majority of the interviewees. Interviewees, directly or indirectly identified a lack
of funding as an obstacle with regards to being able to implement the directives of the
new legislation for the benefit of programmes. In general there was a shared feeling
that meeting these new standards required additional funding which had not been
made available. Interviewee E attributed the funding difficulty to the recession.
Perhaps the most interesting departure for this discussion was around the recognition
that these new standards required more than just money. It would demand for some
perhaps a shift in values, self-awareness and self-reflection as well as other ways of
working. Additionally, it may not be enough for services to keep on doing what had
always been done as at this time a more regulated way seems to be required.

Gillan and Coughlan, state that overall, planning for transition needs to be person-
centred, family-centred, strengths based, and needs led rather than resource led
(2010). An increase in planning on these programmes and a partnership approach with
all stakeholders including the community may be a useful consideration as well as a
resolution of funding issues.

It is also interesting to note that despite the globally acknowledged importance of the
UNCRPD (2007), no interviewee discussed this declaration. When discussing
programmes, interviewees tended to focus on issues relating to families and organisations, as opposed to the rights of PWID.

5.4 Services adapting to support transition programmes

All interviewees seemed to acknowledge that services are being asked to change traditional practices and develop new education-based approaches to provide transition programmes for PWID after secondary education, in line with new policy documentation and legislative standards (New Directions 2012 and HIQA 2009). As disability-service provided transition support programmes are unique in Ireland, a lack of research existed on how these challenges are presented. While there was consensus in the findings on this matter, anomalies existed in how interviewees viewed these challenges.

According to interviewees, challenges varied from organisational changes, effecting staff and building requirements to family issues with moving away from the traditional supports offered by disability services. A number of interviewees reflected on issues relating to providing FETAC accreditation.

This leads the author to a questioning of the relevance of the skills gained from these programmes for PWID. A focus on achieving FETAC accreditation was discussed, however interviewees questioned whether the completion of FETAC accreditation, had useful implications for PWID outside of the programme. It is possible that this may be symptomatic of the courses being provided by disability organisations that are inappropriately awarding FETAC certification, as eluded to by participant R.
In an attempt to explain the phenomenon of services struggling to adapt to providing educational programmes, no interviewee offered any solutions to the various challenges mentioned. This lack of dialogue highlights the overall need for more discourse throughout disability services, with regards to issues surrounding the development and implementation of programmes, to the author.

5.5 Progression after programmes are completed

As discussed by Gillan and Coughlan (2010), barriers exist with regards to the progression of PWID into options after secondary education in Ireland. These include (1) a competitive Irish job market; (2) negative employer attitudes; (3) the loss of disability benefits when a PWID works over 20 hours in a week; and (4) lack of opportunity to develop social networks. In accord with this research, each of the seven interviewees mentioned progression into further options after the programmes conclude as a significant concern for all stakeholders. A negative portrayal of outcomes for students after the programmes were completed was highlighted through all of the transcripts and is captured by interviewee M ‘And then you say what is next for them? Nothing. Sitting inside watching television. I mean, my God. Can you imagine? It must be awful for them.’

The interviewees were vocal in their attempts to assign responsibility for this lack of progressions and, interviewees R and E considered an element of responsibility lying with the programme. Other interviewees referred to a variety of other sources, such as society’s view of PWID, the role played by educational institutes and the negative impact of families with regards to locating this responsibility. However, there was no general agreement about how to allocate responsibility for this lack of progression.
The author has surmised that, in conjunction with statistics regarding low levels of participation of PWID in mainstream education and employment (NIDD 2009) and Irish society’s lack of readiness to include PWID, major challenges exist to achieving an appropriate transition for PWID after service based programmes are completed.

It may be that a paradigm shift challenging societies’ limited understanding of the potential of PWID is required for this to happen but no conclusions can be clearly reached from the existing data. In retrospect, if time had allowed for a second interview or possibly a focus group discussion, the author would have returned to this issue in order to achieve a greater insight into the challenges of progression.

This raises a question about the implementation of policy regarding the social inclusiveness of PWID. This suggests that the extent of the experiences of mainstreaming and social inclusion require further examination at both local and national levels (Gillan and Coughlan 2010).

5.6 The importance of building partnerships

A contributing sub-theme emerged repeatedly, which highlighted the lack of collaboration between disability services providing programmes with external organisations and families of PWID. Interviewees discussed a variety of negative implications resulting from this. These implications correspond with a variety of research, as noted in the literature review (Department of Health 2004, NDA 2004 and Heslop et al. 2002). An important implication, which featured during a number of interviews was the fear felt by families, as a result of being an outsider in the process
of transitioning during and after the completion of programmes. Interviewee E
encapsulates both the importance of building this partnership, as well as the
implication of this challenge by saying ‘you can go ahead in-house and do anything
but you are at nothing without family. Some of them are fearful of what might happen,
risks, dangers.’

The author recognises that the cost-effective development of partnerships may
provide a vital contribution in combating the challenges programmes aimed at
supporting PWID into options after secondary education experience.

5.7 Future considerations for transition programmes

The findings and literature review highlight a need for a reflection on society’s view
of PWID. It is clear that programmes must also develop before these challenges can
be overcome. The author, in conjunction with a framework developed by Hasazi et al.
(1999) attempts to provide a cost-effective, practical framework to facilitate this
development:

(a) Incorporation of system-wide, student and family centric strategies; (b) fostering
of effective and substantive interagency collaboration; (c) facilitation of systemic
professional development; (d) a visionary, supportive, and inclusive form of
leadership; (e) coordination of an integrated set of reform efforts; and (f) emergence
of connections among a variety of local and Governmental transition initiatives.
(p558)
5.8 Conclusion

This research set out to explore some of the challenges of implementing transition Programmes for PWID as perceived by programme managers. In line with the phenomenological approach used in this research, it has not come up with a definitive set of answers to this question. Instead it has identified a number of challenging issues faced by the programme providers, which raise more questions about some of the assumptions that are made in relation to how these programmes function.

While conclusions drawn from the small sample of this research assignment are tentative, this study does echo some themes in the existing literature. It is clear that many barriers remain to successful transitions for the PWID partaking on programmes. It is likely that current difficulties in the economic climate will create even more challenges in terms of addressing gaps in mainstream service provision and in supporting meaningful employment opportunities for this vulnerable group. This issue points to an urgent need for on-going research in this area.

Therefore, there should be an emphasis to address these inequalities and to develop high-quality research to identify additional supports or adjustments required that would benefit people with an intellectual disability (Cooper et al. 2004).

In terms of future research, the transition programmes need further exploration, at both local and national levels, particularly in light of the changing legislative and economic climate. Future studies must explore the views of a wider range of stakeholders including PWID themselves and their families as well as the perspectives
of professionals and staff involved in the transition process to assess whether these 
varying perspectives converge.
Chapter Six: Conclusion

6.1 Introduction

In this ultimate chapter the author will summarise the inquiry thus far. The author will synthesize the epistemological contribution to existing research, identify limitations in the research assignment and conclude by signposting a number of recommendations for the future.

6.2 Chapter summary

The first chapter set the scene for the inquiry. The author highlighted the complexities of the area being researched and the significance of this research assignment due to the fact that very little research currently exists on service-provided programmes aimed at supporting the transition from secondary education to options after secondary education for PWID. The author also presented the research question and the aims and objectives of the research assignment.

Chapter two features a critical and focused review of the literature relevant to the topic of research. An analytical account of the current situation of transitioning within the field of disability studies was presented culminating in a review of the current situation for transition based programmes for PWID leaving secondary education in Ireland and internationally.

In the third chapter the research design was presented beginning with a justification of the chosen methodology. The specific research design employed was outlined. An outline of the method employed for data collection was provided and the chapter
finished with a discussion of the various threats to the validity and reliability of the data collected and the ethical considerations made.

Chapter four outlined the main findings from the qualitative data collection methods used to answer the research question. The findings were presented thematically under the headings; Complying with Legislation and Policy, Providing an educational programme within a disability service; and Progression for PWID after the transition programmes conclude.

The fifth chapter featured the discussion of the author’s findings. This chapter aimed to highlight what was significant about the findings in relation to the research question, with any unexpected, or unanticipated findings considered. This chapter also aimed to establish links between the fields of enquiry identified in the literature review.

6.3 Limitations of the research
The author acknowledges that this research assignment involved a methodological limitation of the somewhat artificial experience of a single interview. One particular limitation the author was aware of in this context involved not having the opportunity for a greater provision of attention to differences in interpretation. Had the author arranged for a focus group involving each of the research participants a greater sense of difference of interpretation of how their sense of challenges faced by the programmes that they are involved with may have been garnered. The author therefore suggests that if this research assignment is repeated a focus group should be used. A further limitation of the single qualitative interview used for this research is
that this study may be difficult to replicate due to the use of open-ended questions (Coolican 2004). Open-ended questions have the potential to provide inefficient access to data, particularly for an inexperienced interviewer who may have an interviewee who is rambling or disorganized, which creates the potential risk of failure to obtain specific detailed content (Kadushin and Kadushin 1997). For this reason the researcher acknowledges the limited conclusiveness of the findings of this research assignment due to its qualitative exploratory nature, however the author encourages the transferability and trustworthiness of this research assignment to be scrutinized by further research (Bauer and Harteis 2012).

The author identified early in the pilot interview that as the interviewees in this research assignment were programme managers of a service who were being interviewed by a front-line staff member, clear barriers were manifesting themselves in the interview. As this phenomenon was identified in the process the interviewer attempted to develop a skilled personal style to put the interviewee at ease (Lee 1993) in order to elicit personal responses that were not the result of the interviewee feeling threatened or uncomfortable in the process.

6.4 Reflection upon the learning process

The journey to reach this destination has been dynamic and complex but in retrospect has acquired simplicity and rhythm. Having worked closely with a programme that aims to support men and women with intellectual disabilities after leaving secondary school, the author became interested in the development and previous research conducted on this form of support. Whilst undertaking this piece of research, a flame was reignited within the author with regards to the need for constant development of
any form of educational programmes being provided. As the great philosopher Heraclitus claimed approximately 2,500 years ago, and recited on the opening page of this dissertation, ‘Everything changes and nothing stands still’. We must meet and embrace this change for the betterment of PWID and more importantly for society.

6.5 Final conclusion

This chapter has summarised the dissertation by reflecting on the chapter outlines and the limitations of the research as well as finally providing a reflection on the personal learning of the author.
References


Appendix A
Participant Information Sheet

Section A: The Research Assignment

1) Title of project: An investigation of issues and challenges facing programmes available to adults with intellectual disabilities in Ireland aimed at supporting the transition beyond secondary education.

2) Purpose and value of study The main purpose of the project is to seek an answer to the question; ‘What programmes aimed at supporting adults transitioning into life after secondary education in Ireland are available and what do these programmes consist of?’

The value of the research is to provide an exploration into an under-researched area.

3) Invitation to participate You have been invited to participate through a calculated selection. There is a two deadline for acceptance of the invitation to partake in the interview process. Your contribution is crucial for the success of this project and would be very much appreciated. This project has been given full unconditional approval from the ethics committee at Trinity College Dublin.

4) Who is organising the research Diarmuid Sinnott, Trinity College Dublin

5) What will happen to the results of the study The results of this research will be collated in Diarmuid Sinnott’s Master Thesis.

6) Contact for further information Diarmuid Sinnott
   email: dsinnott@tcd.ie
   phone: 0851641307

Section B: Your Participation in the Research Assignment

1) Why you have been invited to take part You have been invited to take part in this study because you are a coordinator/service provider of a programme aimed at supporting the transition of adults with intellectual disabilities into options after secondary school.

2) Whether you can refuse to take part You can refuse to take part without having to provide a reason. By informing the researcher that you do not wish to take part in this research, your contact information will be deleted from all and any records kept and will not be contacted further.

3) Whether you can withdraw at any time, and how If you agree to take part in this research, you still have the option to withdraw at anytime by informing the researcher and you are not required to provide a reason for withdrawal.

4) What will happen if you agree to take part (brief description of procedures/tests) An interview will be conducted with you to discuss the challenges faced by the programme that you are involved with. The interview will be digitally recorded and transcribed electronically. Please be assured that the transcribed interviews will not be traceable to you and all personal information will not be included on the transcripts.

5) Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety N/A
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<td>6)</td>
<td>Whether there are any special precautions you must take before, during or after taking part in the study</td>
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<td>7)</td>
<td>What will happen to any information/data/samples that are collected from you</td>
<td>Collected information will be analysed for the research purposes only and secured in password-protected electronic files that only the research team will have access to. None of your personal information will be disclosed or discussed with anyone. Your responses will be treated with complete confidentiality - neither your name nor that of your organisation will be published.</td>
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Appendix B
Consent Form For Participant

Written Consent Form for Participation in Research

An investigation of issues and challenges facing programmes available to adults with intellectual disabilities in Ireland aimed at supporting the transition beyond secondary education.

Lead researcher: Diarmuid Sinnott
Programme of study: Msc. in Disability Studies, Trinity College Dublin
Phone number: 0851641307
E-mail address: dsinnott@tcd.ie

- I understand that if I take part in this study that I will be asked to do partake in an interview about the topic of the transition-based support programme that I am involved and that I will be asked to provide an overview of what this programme entails and the challenges faced during implementation.

- I have spoken with Diarmuid Sinnott and I have had the opportunity to ask questions about this study.

- I understand that the information I give will be anonymised & that my name or other personal identifiers will not be used.

- I can stop answering questions at any time, or end my participation in the study and this will not affect the service provision or treatment I get in any way.

- I understand the results of this study may be published in a thesis, but any personal information I provide will not be identifiable, and the results will be anonymised.

- I understand that all the data I provide will be stored in a secured place, and destroyed after two years in line with the Data Protection Acts 2001/2003.

- I fully understand the procedures involved in the process of audio recording & I give consent to the audio recording of me for the purpose of this research only.
I understand that I can withdraw my consent, or stop participation in the recording at any time, or have all existing recorded sections erased, without any repercussions.

I agree to participate in this study:

Name of participant_________________________
Signature____________________________________________Date___________

Name of researcher_________________________
Signature____________________________________________Date___________

I agree to be audio-taped for the purpose of this study only:

Name of participant_________________________
Signature____________________________________________Date___________

Name of researcher_________________________
Signature____________________________________________Date___________
Appendix C
Semi-structured Interview

A. Introduction
Thank you for meeting me today. I will be asking some questions today with regards to the transition-based programme that you are involved with. The interview will last between 45 and 60 minutes. I would like to ask your permission to audio record this interview? The data I record will be kept safe on my computer and anonymised. You do not have to answer any questions that you don’t want to and can withdraw from the interview without penalty at any stage. Would you like to ask me any questions before we start?

B. Programme description

• Outline of programme:
  o Describe the programme:
  o How many days of the week are involved?
  o What location are programme sessions held in?
  o Who facilitates learning on the programme? Are they internal or external to your organisation?
  o How is the programme funded?

• Student information:
  o How many students are currently partaking on the programme?
  o What is the gender mix of the group?
  o How are students informed about the programme?

• Purpose of programme:
  o What are the main aims of the programme?:
  o Interesting, do you think that the participants are aware of this?
  o Where did these aims come from?

C. Challenges faced in the implementation of programme

• What do you think are the main challenges to the successful implementation of the programme?
  o Are outside influences such as participant’s family members ever a negative factor?

D. Recommendations for future programme development

• If you were giving advice to a person setting up a transition-based programme, such as yours would you have any advice as to how best to approach the development?
  o Are the any very positive developments that have come about as a result of the programme being implemented?
o Are there any obstacles to avoid when developing a programme such as yours?

E. Conclusion

- Are there any other key issues you would like to raise that have not been covered in this interview?
- Can I contact you by telephone if there are any points I need to follow up on at a later stage?
### Appendix D

**Initial Codes**

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Appendix E
Reoccurring codes

(ACC)Accreditation (SKD)Skills deficits
(ADH)Adulthood (SOI)Social Inclusion
(AGE)Agency (SOC)Society
(AGR)Agency referral (STA)Stakeholders
(ASP)Aspirations (STD)Standardised
(BAS)Basic skills (SUS)Supports
(CAR)Caring (TER)Terror
(CHA)Challenge (TRA)Traditional
(CHI)Child (COL)Collaboration
(COM)Communication (CTL)Control
(CUL)Culture (DEP)Dependency
(DBP)Dictated by policy (DIF)Differing expectations
(DIS)Disappointment (ENP)End point
(ETH)Ethnic singularity (EVA)Evaluation
(EXS)Expectations (FAI)Failure
(FRI)Friendships (FUM)Functionalism
(FUN)Funding (HOM)Homogenous
(IND)Individualised (LIS)Life skills
(LOG)Logistics (MAT)Maturity
(MOT)Motivation (NOR)Norms
(OBD)Old big disability family (PAR)Parents
(PEI)Personal interaction (PEC)Person-centeredness
(POW)Power (PRE)Predictably
(REA)Reality (REG)Regulations
(ROL)Rolling out (SHT)Short-term

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Appendix F
Sample Transcription

Example of a transcribed interview with a programme manager

Interviewer pseudonym: D
Interviewee pseudonym: N
Date of interview: June 2014

D: Eh, thanks for meeting me today. I will be asking some questions with regards to the transition-based programme that you are involved with. The interview will last approximately thirty to forty five minutes. As we discussed this interview will be digitally recorded. The data I recorded will be kept safe on my computer and anonymised. You do not have to answer any questions that you don’t want to and you can withdraw from the interview at any stage. Would you like to ask me any questions before we start?

N: No, no I’m good to start.

D: Perfect. Emm, could you describe the programme that you are involved with.

N: The programme that we have for school leavers has been running since 2009, okay. So we’ve run this programme every two years since 2009, umm, incidentally, now we’re probably going to run on a yearly basis because I suppose demand for programmes, basic skills programmes for school leavers is on the increase in the locality. We, um, as I said it’s a two year programme, we keep it as community based as possible and by community based I mean we try to keep it in the community, we book rooms in the locality, so we try to keep it where the bus stops are, you know where everything is happening, as opposed to on campuses or in industrial estates or in schools for that matter. Emm, we also hire, in the main or tutors, if we can’t get them for free in various organisations, for example MABS might help us in terms of money management, but more often than not we would have to buy in our tutors, which is a good thing, because you can buy in a person for a period of time and move on, spend your money elsewhere, we also have a core group of support workers, umm that would make sure that the tutors are booked, that the rooms are booked that the men and women are supported to turn up on time, travel trained, risk assessed, all that background stuff that needs to be done, that tutors aren’t going to do. We take referrals I suppose from everywhere, we I suppose we have taken school leavers and it’s not unknown to take somebody who left school a year or two before maybe had a bad time or maybe got ill, to come on the programme, which if it suits them we can do that. But in the main nine out of ten times would be a school leaver. We tend to run groups of maybe eight to ten people, no more than that with the first year heavily based on a group mentality, people getting together, learning together, creating friendships, so on so forth, kind of college mentality and then with a view in the second year, certainly to start thinking about moving on maybe to pickup on the course that they themselves would prefer in an area, they would like, even a location they would like, so things tend to get individualised starting in year two but certainly by the time the programme is finished, people would move on to their own area of interest and (organisation) would always make sure, where possible the person would have a destination booked, secured mm and if possible again with some support,
funding from the HSE where we would stay I suppose, in the background, to make sure that maybe the good work that we put in, maybe doesn’t get lost along the way that somebody moves to a new college and that things don’t work out in the first week, that maybe they drop out, we would make sure that a support worker would be around certainly for that transition period, to make sure that things worked out well.

D: Sounds good. Emm, can I ask you about the gender mix, is there a sort of trend towards one gender or how does it roll out?

N: That’s a good question, I think in the main we tend to at the start we tended to have a, a good mix, roughly 50/50 (pause) mm but of late I think we are moving a little bit towards male, yeah it seems to be heading a little bit towards male, also what’s happening is, in terms of trends, I know that (name of school) which is a (service) school we would get a lot of referrals from there and those referrals seems to be increasing over the years, so that whilst you have a pattern of more males coming forward I suppose you have a pattern of people who need more basic skills training than probably would have been the case ten years ago, mmm my understanding is the kids graduating from say (school) would have in the main gone to (specific college) or maybe to work straight away from school but I think that’s not the case anymore, obviously I think work is harder to find but I think certainly the ability of level doesn’t seem to be as high as it used to be.

D: Huh, that’s interesting. We might come back to that. Can I ask you what the main aims of the programme are? What does it aim to achieve?

N: Well I suppose the over arching aim is to assist people to mature, I suppose academically and independent living skills. The two years in itself, mm helps a lot, people just literally grow up, they mature and that helps but our is to ensure that people travel safely and independently, can turn up on time, if they are supposed to have materials for a class or for an event that they would have those materials with them, mmm that they understand their money better, that their parents I suppose develop a new more mature relationship with them. They move from children to being adults at home, as opposed to children at home, which I suppose is a whole different thing. So for us it’s about that two years of a maturation, where I suppose people are better prepared to go to (specific college) or I suppose better prepared to go to take on a job coach and to work with them to get a job. I mean quite frankly most of the students that come to us now, aged 18 wouldn’t be able to sustain a job, probably wouldn’t be able to travel to the workplace, probably wouldn’t be able to be on time enough, wouldn’t take instruction as well as they might need to, if they went to college if an assignment was too difficult would probably drop-out for fear of handing in something that was below par would probably drop. So those two years we try to eradicate a lot of those threats because obviously if a person gets a job coach straight from school and it fails, that has a major impact. So we are trying to avoid that and likewise if they are going to a college and it doesn’t go well it tends to have a profound impact so we are trying to avoid that to make sure that their first step would be a positive one.

D: Sounds good. Emm, do you think that the participants are aware of that aim when they come to the programme?
N: Now that’s a very good question. (pause) We would always be concerned really as to what the motivation, I suppose certainly of the participants, what their motivations would be, I’m not going to lie, certainly when they come to the first information sessions, you have these very young people who are half terrified, half excited, you can tell when you speak that half the words go in and that the other half doesn’t, in some ways it can be the same way, with some parents. So certainly people’s understanding of why they are coming to the programme, whilst we try to reaffirm it, as often as possible in different ways, for example having a verbal information sessions, sending out some paperwork on the programme, so trying to repeat the message in different ways, you would wonder about how much the men and women coming on a programme, understand what they are about to do. That said thinking back to my own college days; I really had no idea of what I was getting myself into either.

D: Yeah.

N: So I don’t really know that the intellectual disability piece is a significant factor. I think a lot of it has to do with age and just that fission when you are making a big life move. So we do, I think the message gets home pretty quick once they start the programme, and in the first few weeks they spend a lot of time with the support staff and that’s a real opportunity to eh, you know as you walk from bus stop to bus stop, for questions to be asked, people pick up the information pretty quick in a more relaxed way.

D: In relation to the timetable of activities, how is that developed?

N: In many ways, I suppose we’ve had four or five groups over many years, so it’s kind of tried and trusted, so things have worked which we keep, something’s haven’t worked which we no longer do, in the main first time around we would have consulted with the participants and certainly the people for example in the schools that would have referred them and their parents. So we would have put together a pretty standard basic programme and then worked it on from there. The VEC provide part of programme and we are some what bound by the hours they can provide, the locations that they provide and the tutors that they can provide because that dictates the subject matter that they would provide. Now in the main it tends to be quite suitable, quite related and so on and so forth but to a degree that would be sort of out of our control. But we do tend to listen if for example there was em, an issue arising in the group, for example interpersonal relations in the group we would respond pretty quickly to that and then put on maybe an eight week programme, hire a tutor skilled in the area and obviously a good understanding of working with people with disabilities. So we would provide that programme to that particular group to address that issue emm, but we do tend to stick to you know, a standard timetable that we tend to stick to over the years now, barring availability issues, that’s the programme basically picks itself. (10.29)

D: Makes sense. And, eh in relation to topics, what are the fundamental learning goals from the timetable, what are you trying to get?

N: Yeah well certainly, the timetable wouldn’t be academic in nature, while their would be some classroom activity most of the outcomes that we are trying to achieve
are in the less, in the kind of non-academic area, so for example independent travel would be really important, interpersonal relationships would be really important, you know that getting into intimacy and intimate relationships, we would make sure that some work was done in that area, as we said we want people to be on time to understand that I suppose the world is largely about rules and regulations and you know if you have a job if you have to observe all kinds of things, if you are on a training course, you have to observe all sorts, if you live at home, you have to observe all sorts, so it’s to get the people turning up on time, understanding time, understanding their money, understanding how to interact with people on many levels certainly to travel independently, and then I suppose once they have those skills to be able to make decisions for themselves, to be able to make choices for themselves but to think about the ramifications of those choices and decisions, you can say oh I want a job but if the job is going to be far away from home and does that mean that you will have to move far away from home and you can’t be, you know, you can’t make decisions that you can’t back fill I suppose, so they would be the overriding I suppose areas that we would like to be successful in, certainly in the early parts of the programme.

D: Excellent. Okay so I think that we have a good background to the programme and where it is coming from and what it does and what it aims to do. Mm, the second part of the interview is focusing on the issues and challenges of running a programme, and so far you’ve already mentioned a sort of increase in numbers. What kind of role is that playing in implementing a programme?

N: Well demand has gone up, we used to run the programme every two years and now on occasion we run it every year, depending on demand and now what happens is the HSE usually make contact with us and say we have a huge amount for school leavers this year, we need a basic skills programme and they will talk us, I suppose about funding about how we could make that programme happen, mm, because if it’s a two year programme and we run it every year, obviously we need a double set of rooms and tutors and background staff and so on and so forth, so that increase in demand is definitely a challenge but in the main it really is a financial challenge only. It is possible to replicate the programme which is I suppose one of the original points of the programme that it would be (pause)

D: Replicable?

N: Yes replicable as opposed to replicatable, so I suppose it is easy to run two at the same time, once the funding is there and the HSE have always been very forth coming it has to be said, if they’ve needed the programme they have been willing to fund the programme.

D: And you alluded to it already but where is this increase coming from? Mm do you have any understanding of why it’s happening?

N: Well I think, I think there’s many reasons, I think first of all there seems to be, I don’t have evidence for this, people with disabilities coming through, certainly (service), don’t seem to be as able at 18, as they used to be in the past. So there is a need for more basic skills training, hence our programme. I think also people who probably would have just finished in school and went to a more campus, based you
know sheltered workshop, wouldn’t dream of doing that now and are now keener to find a basic skills programme that is community based that will enable them to avoid a campus based space, future. Certainly New Directions which is a recent HSE policy on Day Supports or meaningful supports for people, it would, I mean the programme would be very much built around what New Directions very much sees as a proper, you know, programme for people in 2014. So you know, because that programme is now out there, it’s kind of publicising itself, it’s creating its own demand because people word of mouth since 2009, people are aware of it now, where they might not have been aware of it before, so we do get more self-referrals or families ringing us, even couple of years in advance to say, can I put my particular son or daughter’s name down for that programme?

D: Interesting and that leads us to a whole set of other questions in relation to New Directions and legislation and policies, how are they affecting the programmes that are ran here?

N: Well as I said, first of all they wouldn’t have been driving this programme at the time it was originally designed, even though New Directions didn’t exist, I think in 2009 you could tell that the talk in HSE that was going to lead to New Directions, we would have been aware of those beliefs and philosophies in 2009 and we would have made sure that, to design the future programme based on those, umm, I think New Directions is about making sure that people have an opportunity to have the life of an individual as opposed to the life of a person who is a part of a big disability family, emm, so what we’ve been trying to do is make sure that people have the benefits of the old big disability family but then eh, I suppose none of the negatives that have started to be affiliated with that. So we have the (service organisation) mother ship, if you like, but we don’t encourage people to come to those buildings, we encourage people to meet their support worker in their local community, as soon as they start on the programme to make sure that they know the programme is only for a period of time, at some point they will move on and they will leave their friends behind at some point if they want or they, if they want to sustain those friendships that they do it on their own terms on their own basis not in our canteen or not in our swimming pool, in the local swimming pool or in the local Starbucks. So New Directions, governs our programme but it governs well it’s certainly supposed to govern every day support, or everyday programme that is in evidence in Ireland. So person centred planning has to be there, liaison with families has to be there, the programme has to be as individualised as possible, finances can’t be seen to be dictating the types of programmes that you are providing, they should really be enabling the type of programme that you are providing, to have a good programme under New Directions you need to have good relationships certainly with the HSE because they fund it, you need to have good relationships with the community because there are huge amount of resources, that don’t cost anything, we only get them by having good relationships, we only get them by having good relationships, so that’s New Directions, that’s the philosophy that’s driving our programme, but it’s also the philosophy that’s starting to drive other agencies, we get referral’s now from other agencies, we weren’t getting referrals from other agencies before and it’s starting to drive some of the families because families are world wise nowadays, hey look on the internet the read these policies, I have families that come to me and say I read New Direction, that’s the talk that they’re talking now, so I don’t need to be telling them this type of stuff any more, they’re telling me.
D: Huh, and is there a challenge associated with all these new expectations of services and particularly these programmes that you listed there 5 or 6 very good expectations of the programme but on a practical level meeting those expectations, is that a challenge?

N: Well it, it is it’s a surmountable one in the sense that we’ve overcome any challenges, I think that, one issue, not that you don’t have control over but we put a lot of work in hence the relationship building. I think one challenge, can be around families, can be in the sense around families, moving in a sense to the first non-school programme, families do find that a bit of a struggle particularly around safety, you know they may have, the child I suppose may have got a bus or a lift to school for example, day in day out and are now expected, you know to ravel across the city on maybe a bus or two buses, that’s a big ask for families, that’s a big challenge and that’s a challenge that starts from the very first day, umm that needs to be overcome. So that’s always a challenge. I mean funding is always a challenge but to date the HSE have been, you know, have stepped up to mark which is fantastic, the VEC have also as a big partner, I suppose every two years, they do provide accommodation, rooms, classrooms and so on. So the challenges have been surmountable so far.

D: Excellent. So that brings us on to families then, mm, families and parents are a key point, you mentioned there families being unsure about safety, is it ever an issue where families have so many concerns that the participant is held back in any way?

N: It’s rare, it does happen. A stand out one would be, we had a lady from mm, the travelling community who really struggled I suppose with her family to become part of the programme, I think they might have saw it very much as something that the settled community were doing, I think you had the intellectual disability piece as well. But it was a struggle, the lady attended the programme for the two years, she successfully completed the programme, so we got through, unfortunately then when she chose her next step and she secured a place on a course, I think then the travelling community bug, maybe, kicked back in and eh, she didn’t take her place on the course and the decision that the family made was that she would be better just to come back to the travelling community, mm, all good it ‘s everybody choice but that would have been a challenge. We haven’t had any other, I suppose, shall we say ethnic groups or groups like that since, so I can’t say you know how it would pan out with other groups, every else has been you know, homogenous you know, so that’s been a challenge I suppose for other families I think that we’ve gotten there in the end, they do want to make the right decision and they do want to be convinced, so giving them every opportunity to going on this programme is the right thing to do for the son or daughter.

D: Can’t ask for much more than that. So outcomes then that lead to outcomes you mentioned there after the programme is completed, is it a challenge in finding suitable places for the people to go?

N: Yes I suppose it is, mm, interestingly there’s not may at the age of 20, 21 there’s not many who want to work, they’re still quite young and it’s something we encourage people to stay on in education for as long as possible, because we feel if you are lucky enough to get a job at 21 you are very unlikely to go back to education,
so I suppose while we will accommodate people who want to work we encourage people who want to stay in education. It’s a challenge but once again, I think in the main we can find suitable places for people, they might be a little last minute by the time you get everybody settled and sorted but that’s just the nature of things but that in the nature. We do have for example, the outcomes for the 2009 programme we had 8 people on the programme, two people went into part-time work, of which one is still doing and we assign job coaches in both cases, four people went to further education, which I believe certainly would be still doing in some shape or form, and two would I suppose have dropped out and one being I suppose the lady from the travelling community and another man who just didn’t know what he wanted to do and five years later, I met him recently still doesn’t know what he wants to do. Doesn’t work, doesn’t study. Hangs around and does his own thing. So they would be our outcomes from 2009 and we would evaluate the programme then every two years, when the programme ends we would get somebody to track you know the outcomes for people and over the years keep an eye on them. But we would have been very happy, using the 2009 outcomes; we would have been satisfied with the outcomes.

D: Sure, mmm do you ever have the flipside of the family members situation and it leads into family members as well, where mm, expectations may be too high or maybe of the participant, where I am going to come to this programme and get something that is not attainable for that person. Is that?

N: Eh I would have to say no, in my experience. I haven’t heard of that being an issue where mum or dad or even the participant has really high expectations, umm, we get some families and some participants who have a very firm view of what they want to do, but I think, which may be very hard to achieve, for example working in TV. Or something like that but I think we do find maybe the right course that would have some link I suppose to working in an area like that. But these areas are hard for anyone to get a go, to get a start in. What do you do, you pick a course that’s going to leave you somewhere close to it and you’re just hoping for the best, so it hasn’t been a huge challenge, I think we managed to negotiate it, I have to say.

D: Excellent you mentioned, when you were talking about creating the programme and it was designed with the participants, is there ever any collaboration with disability services with regards to the programme.

N: No, mmm, kinda (sic.) quite the opposite to be honest with you. I know the VEC part of the programme is open to other, eh, disability providers and I know other disability providers would send some students there but in terms of others designing our programme or running our programme, we’d to the best of my knowledge no we don’t link to any other disability type organisations, quite the opposite, we tend to stay away from in the sense that we want they guys to link in with just general community based providers, be it citizen’s information or whatever it might be MABs, eh the social welfare office, FÁS as it was, so on and so forth, so those are the sort of providers or agencies that we’re making friend with or doing business with.

D: Eh and in terms of, sort of designing and where you get you research from, where the creation of this programme is coming from, is there information out there?
N: If I’m honest we originally designed the programme on, based on the needs of a large group of students coming from *(school name)* that’s how the original programme was designed, emm. We got very good information from their personal plans, from their tutors that their skills deficits were x, y and z and that we build the programme around those and that their skills positives were a, b and c so that’s how the original programme was constructed, obviously with New Directions in mind, with some input from the men and women who wanted to come on the programme and to a lesser extent I suppose their families, mm but that would have been where we got our information originally but if I’m honest that’s where we still get our information, it comes from the referral source, it comes from the family, it comes from the participant, it doesn’t tend to come from other organisations, disability providers or any research.

D: Okay, it sounds like there is not much research out there, or there is not much of a protocol for these programmes, would I be correct in saying that?

N: I would say that would be correct. I mean I’m not 100% sure. We would have *(name) in *(organisation)* would have pieced together a lot of the original programme with myself and *(name)* from *(school)* and we would certainly at looked at what sort of basic skills programmes where out there for people with I.D. umm there wasn’t a huge amount of information for community based programmes. You could find plenty of community based programmes, in a centre or a big disability provider like umm, *(Disability Organisation)* for example, they have been doing it for years and doing it quite well but not in a community based way, mmm, so we were very keen to provide that opportunity I think for the people we were going to have to support.

D: Interesting. Ummm, balances the challenges of providing an educational programme which is trying to meet New Directions goals and be based in the community, whilst also being a disability service at the same time, that crossover, do any challenges emerge from that?

N: Umm, yeah well I mean to use New Directions as your guide really means that you’ve got to regenerate your service this organisation has been in operation since 96, umm and over the years we have provided a lot of I suppose, cutting edge supports but I suppose what’s cutting edge in 1992 is not going to be cutting edge in 2002, so we’ve, New Directions has really driven us to reform and regenerate I suppose a lot of what we do, we did have sheltered work, we do still have some, but we probably have only about 20% of what we had five years ago and that’s very much driven by New Directions. It’s a big challenge for the organisation, it’s a big challenge for families to hear that their son or daughter are no longer going to be coming to the same building are going to be based in different localities and moving around a lot more, it’s a big issue for staff who have come to the same building for years, to do the same sort of work, quite frankly it’s a big issue for the building because you use your building in a different way, you’ve got to move desks, I suppose the whole ergonomic, parking, so it’s massive. New Directions drives major change, I would say we’ve been at this five years and it’s probably taken five years, to get to phase one, in my view, of beginning *(organisation)* in line, with best practice.

D: So it’s a slow process.
N: It’s a slow process and correctly, to do it correctly it needs to be a slow process, there isn’t any other way to do it, I think anyone that says they read New Directions and turned their service around in 12 months is probably deluding themselves, I would say.

D: Interesting. Eh, I have two more areas, accreditation on then programmes, where does it come from and what does it look like?

N: The VEC will accredit everything they do at FETAC level usually 3, sometimes 2 or 4. So the academic accreditation is done but the VEC or ETB as its now know. The rest of the programme we don’t accredit, ummm it’s run by (organisation), it tends to be run by (organisation’s) staff or or or tutors that we hire in. That part of the programme isn’t accredited, we give a cert. at the end of the two-year programme but it wouldn’t be recognised in the sense of a FETAC module, okay.

D: Mmm, last now is in relation to new programmes getting setup. My research is trying to inform these types of programmes, now would you have any recommendations or any key points of learning for somebody setting up a programme, tomorrow?

N: For setting up a programme for school leavers?

D: Yeah.

N: Or for?

D: So for setting up exactly what’s going on here but maybe in a different locality or country even? What’s the key learning that you’ve gained from 5 years of running these types of programmes?

N: Well certainly is to make sure that families are involved at the earliest point and obviously that the men and women are involved themselves. Promotion of the programme around where the referrals might come from, your local HSE, you local schools, social work team, primary care, people like that. It’s very important to get the information out there to ensure you’re going to have people feeding in the right information, for example if it’s going to be rurally based it’s going to be much different to our programme which is very urban, so it is very important to get the stakeholders together very, very quickly. Funding is key, so the key stakeholder is who is going to pay for the programme? So that has got to be sorted pretty quickly, ehh, I would say that the outcomes obviously, where you, the two years goes pretty quick so you need to know as soon as your induction is over and the programme really starts to roll almost six weeks later, staff need to get together and say listen, what are we going to do in two years time because the outcomes for people are pretty predictable, they are going to want to go on courses, they are going to want to maybe find part-time work, so are you going to have job coaches ready, are you going to have education support worker’s ready in two years and to do that, funding once again needs to be sourced and that takes a little bit of time. So definitely your partners or your stakeholders are key and umm, they need to be cultivated, so lots of cups of coffee are required, particularly at the start of the programme when it’s from scratch. It tends to be very self-perpetuating I suppose if that’s the word, after it’s been run
once the refers know who you are, your funders know who you are, you tend to get you name around the place, a good programme it tends to get out there. But you’re first time out is your maiden voyage and you need to have your stakeholders.

D: Huh, excellent is there anything you’d like to add (name)?

N: Umm, no just the point that I did make a personal think for me, once people finish the programme, I like (this organisation) funded by the HSE to keep linked in with the person. Something we’ve agonised about, do you just cut the person loose and they sink or swim and eh, you know it allows them to move away shall we say from a disability provider, they can go off and get their own course or job and do their own thing, um I feel that we should stay linked in, I feel that people with intellectual disability, while they might get a good run for a period, but that run usually comes to an end and it’s at that point that people get lost in the mix, when the first job ends, when the course finishes

D: Yeah.

N: that’s when they get lost and eh, inevitably my view will come back after 10 years of living on their own, personal hygiene has gone to pot, they’ve lost their literacy skills they’ve lost their interpersonal skills, eh and it’s a huge job for a service then to regenerate them of reintegrate them.

D: Um, um

N: (Pause) So my view is keep the links, keep them simple basic, don’t overdo it, watch from afar where possible but I think watch from afar is essential.

D: Very interesting, that’s a new piece of learning there for me, okay thanks very much, I’ll stop the recording there.