

**An Exploration of Social Inclusion and Employment: A Study from  
the perspectives of people with intellectual disability and mental  
health problems**

**Master of Science in Disability Studies**

**2013**

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## DECLARATION

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Genevieve Ruiz O'Sullivan

## **SUMMARY**

The origin of this study coincides with the current Irish National Disability Strategy and the increasing interest in improving the living conditions of people with disabilities, providing them with community-based settings and for them to enjoy full inclusion in the community. The United Nations Convention of the Rights of Persons with Disabilities (CRPD) has been an important milestone in raising concern over the rights of people with disability. This study focuses specifically on two rights contained in the CRPD: living independently and being included in the community and employment. However, previous research has found that the perspectives of people with disabilities in these areas are often ignored. Furthermore, there is scarce research available from the perspectives of disabled people who are in employment situations giving account of their experiences in the places where they live.

This study conducted a secondary data analysis on data collected as part of a wider longitudinal study aiming to evaluate personalised support across services assisting people with disabilities to move to community-based settings or independent living. This mixed methods study sought to 1) explore the paid employment and voluntary work status amongst people with intellectual disability (ID) and mental health problems (MHP) in a sample of the wider study, through descriptive statistics; 2) identify the relation between being employed and the community activity levels through inferential statistics; and 3) explore the life experiences for those in employment situations, both, paid employment and voluntary work, across different types of accommodation available to them, through case study methodology.

Due to the complexity of the phenomenon, a mixed methods approach was selected to reach the aims of this study. This mixed methods research was sequential and explanatory in design as analysis of quantitative data preceded the qualitative data access and analysis, identifying the sample for the qualitative phase. The sampling criteria were to be engaged in paid employment or engaged in voluntary work.

The results of the quantitative phase of this study showed that the sample with ID had slightly higher rates in both paid employment and voluntary work compared with the sample with MHP. Furthermore, an independent samples *t*-test was conducted to compare levels of community activity between employed and unemployed adults with disabilities (ID and MHP). There was a significant difference in the scores

between those employed and unemployed,  $t(74) = -2.53, p > .05$ , ( $M = 3.93, SD = 1.94$ ) scoring higher than unemployed individuals ( $M = 2.47, SD = 1.99$ ). The magnitude of the differences in the means (mean difference =  $-1.46$ , 95% CI:  $-2.66$  to  $-.27$ ) was medium ( $\eta^2 = .07$ ). These results suggested that employment status affected the levels of community activity; more specifically, that individuals with ID or MHP who were employed participated in more activities in the community than those unemployed. In the qualitative phase of this study, nine adults were chosen from the quantitative phase, forming three case studies corresponding to the types of accommodation where the sample was living: personalised settings ( $n = 4$ ), congregated settings ( $n = 3$ ) and the family home ( $n = 2$ ). Participants, their relatives and their key workers were interviewed through open ended questions. There were a total of 21 interviews. Interview data was examined for differences and similarities in experiences across the various types of settings. A cross-case analysis revealed categories substantiated in the existent literature: 1) environmental differences across settings; 2) independence and independent living skills; 3) decision making and empowerment; 4) community activities and relationships with people; 5) employment; 6) expectations for the future; and 7) different supports leading to different results. The findings of this study emphasised the perspectives of people with ID and MHP thoroughly.

The results of this study revealed, from the perspective of the person with disability, the necessity to reassess and address the lack of support provided by some services when 'moving' people with disabilities from congregated settings to personalised or community-based settings. It also underlined that parents of persons with disabilities living in the family home play a fundamental role in locating job opportunities for them, while those living in personalised settings are assisted on that issue mostly by their key workers. None of the participants mentioned services helping them to locate job opportunities. Therefore, this study questions the planning that the current Irish National Disability Strategy have in relation to consulting people with disabilities on the important matters of deciding where and with whom to live, as well as the support that they are offering to them in the process of de-institutionalisation, having access to community activities and to joining the work force. Finally, this study emphasised from a Disability Studies perspective the need for more research where people with disabilities are included and consulted.

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## List of Abbreviations

|      |  |
|------|--|
| ID   | Intellectual disability  |
| MHP  | Mental Health Problems   |
| CRPD | United Nations Convention on the Rights of Persons with Disabilities |
| ILS  | Independent living Skills  |
| NDA  | National Disability Authority  |
| DFI  | Disability Federation of Ireland                                     |
| WHO  | World Health Organisation  |
| FRA  | European Union Agency For Fundamental Rights                         |
| HSE  | Health Service Executive   |
| REAC | Research Ethical Approval Committee                                  |
| SPSS | Statistical Package for the Social Sciences                          |
| TCD  | Trinity College Dublin   |



## **ACKNOWLEDGEMENTS**

I would like to acknowledge the people who made the writing of this dissertation a unique, powerful and unforgettable experience. I found support in many ways along this learning process, and for that I am very thankful.

First I would like to express my gratitude to the all the participants in this study for sharing your thoughts, your feelings and experiences. I would like to acknowledge Dr. Roy McConkey and all the team of 'the Genio Project' for giving me the opportunity to access to the data analysed in this study.

A special gratitude I give to my supervisor, Dr. Garcia-Iriarte for the helpful comments provided on earlier drafts of this study and most importantly for guiding me to grow as a student.

My family, for their encouragement and support and because despite the ocean that keep us apart always are there for me. My mother, Maria Del Carmen Ruiz Hernandez for being my inspiration and to my husband Michael O'Sullivan for being there unconditionally.

## DEDICATION

*To my mother, for inspiring me to pursuing my dreams, for all the support across the miles: Gracias mamá.*

*To my husband, simply for being the way you are, for that, and for the tons of love, support and the chocolate you gave me: Thank you.*

# 1. INTRODUCTION

## 1.1 Introduction

This chapter provides a historical overview of the institutionalisation of people with disabilities and with mental health problems, and introduces the concept of independent living, so as to understand the living circumstances that people with disabilities have experienced. Using some statistical references, this chapter identifies where people with disabilities live in contemporary Ireland. The terms 'employment' and 'social inclusion' are defined within the context of disability as those are key aspects of this study. Moreover, the aims and the rationale for the choice of methodology are also provided in this chapter. Finally, this introductory chapter concludes outlining the study's structure.

## 1.2 Accommodation for people with disabilities: A historical perspective.

At the beginning of the nineteenth century institutionalisation and segregation were considered appropriate solutions to shelter people with disabilities or for those considered unfit to work (McDonnell, 2007). Institutions for disabled people originated as a humane response to the oppression and misery created by the new demands of increasing industrialised communities (Ericsson & Mansell, 1996; Mansell & Beadle-Brown, 2010; WHO, 2011; Barnes & Mercer, 2005) and were often the preferred choice by many families who struggled with criticisms from society (Knapp et al, 2011, p.114). The construction of institutions for disabled people made evident the confiscation of their right of choice, specifically related to where and with whom to live (Barnes & Mercer, 2005; Stewart, Harris & Sapey, 1999). Although one of the ideologies in creating institutions for disabled people was the one of protecting and providing adequate assistance, soon the conditions in institutions deteriorated and residents experienced isolation and poor care conditions (McDonnell, 2007; Geurts, 2011). There are documented reports, from diverse countries, that attest that abuses of a physical, sexual and/or emotional nature are common practices within the

institutional settings for the disabled and the mentally ill (Rosenthal, Jehn & Galvan, 2011; Conroy, 2012; Beadle-Brown et al., 2010).

After the Second World War many countries started to consider alternatives to institutionalization such as providing support to people with disabilities in the community (Mansell & Beadle-Brown, 2010). As Mansell et al. (2007) note, a major contributor that has influenced the transition from institutionalization is "*The Independent Living Movement*". This movement has its origins in the USA in the 1960's when disability activists organised to protest towards a shift in both policy and the perception of disability. Soon after, Centres for Independent Living were created and directed by disabled people, seeking to offer a range of services which would allow disabled people to be included in the community (Barnes & Mercer, 2005). The philosophy of independent living is based on four assumptions: all human life is of value; that anyone, regardless of their impairment is capable of exerting choice; that people who are disabled by society have the right to assert control over their own lives and finally, that people with disabilities have the right to participate fully in society (Gillinson, Green & Miller, 2005). Therefore, independent living does not only refer to a physical setting, but to change the power connection between the assisted and the assistant, empowering people with disabilities to transcend from a traditional passive status to an active one, in control of their lives (Finkelstein, 1980).

The interest and research in relation to Independent Living and social inclusion had increased in the last few years. A milestone is The United Nations Convention on the Rights of Persons with Disabilities (CRPD), which states the rights of disabled people and Article 19 stipulates the right to live independently and to be included in the community. Although some European Nations, like Ireland, had not ratified it yet, all EU Member States signed the Convention in 2012.

In many countries, institutions still persist. Sweden and Norway are the only two countries where the closing of all institutions has been achieved, thus those nations are considered leaders in the field (Ericsson, 2002). In a recent European study, it was reported that there were over a million people with disabilities living in residential institutes in Europe; emphasizing the need to address the issue in order to ensure

that everyone, regardless their abilities enjoy their rights with equality (Mansell et al., 2007).

### **1.3 Accommodation for people with disabilities in Ireland**

It was until the 1950s when community-based settings began to emerge as a result of the union and efforts of parents and groups of individuals with intellectual disability (ID) (HSE, 2011) and despite many changes which have occurred in the last 40 years, the Irish National Disability Authority stated only a few years ago that people with disabilities live unequal lives and are at higher risk of social exclusion compared to the rest of the population (NDA, 2005).

In the 2006 Census in Ireland, 16% of the population reported a psychological or emotional condition, while 18% reported ID. In 2011, there were 27,324 people registered on the National Intellectual Disability Database (NIDD); 30.1% of whom were living in full-time residential services; 66% lived at home with parents, sibling's relatives or foster parents and less than 1% was accommodated in psychiatric hospitals (Kelly, 2011). However, Conroy (2013) states that the national census carried out in 2011, is a much wider measurement, because it also includes those individuals not using services for disabled people and those whose disability is relatively slight; counting a total of 57,709 people with ID. Furthermore, the Health Service Executive (HSE) (2011) states that almost 3,800 persons with intellectual disabilities are still living in congregated settings in Ireland (not including nursing homes, residential care centres for people with autism, mental health settings and Intentional Communities).

Therefore, all evidence collected indicates that the vast majority of people with intellectual disability and mental health problems are not living independently. While some rely on the support of family members, others remain in institutions and only a small but growing number are living within the community. Regardless of the lack of accurate data indicating the number of people with ID and those with MHP living in personalised accommodation, or in any other setting, the literature suggests that it is possible for both groups being integrated into the community. However, the possibility

of living independently is subject to the type and degree of support provided to them (European Union Agency for Fundamental Rights, 2012).

#### **1.4 Independent and community living in Ireland for people with disabilities**

As with other countries in Europe, Ireland has set an agenda in relation to de-institutionalisation. The publication *“Time to Move on from Congregated Settings: A Strategy for Community Inclusion”* states the aim of the National Disability Strategy to close all the remaining institutes, and to relocate the residents in community-based settings and proposed that living arrangements should be in ordinary neighbourhoods in the community with individualised supports (HSE, 2011).

For people with disabilities social inclusion includes having appropriate living accommodation, employment and adequate support, among other factors (Hall, 2005). Thus, to guarantee the right to independent living and being included in the community requires not only housing policies, but employment policies and real opportunities to participate economically, socially and politically.

#### **1.5 Paid employment and voluntary work**

Traditionally large psychiatric hospitals and institutions for people with ID provided sheltered workshops/work services. While they offered work opportunities for disabled people, they also contributed to their segregation (McDonnell, 2007) depriving them from experiencing ordinary working environments and routines.

Stuart (2006) argues that there is no other social activity that provides a greater sense of self-worth than work. Employment, including voluntary work is a key factor to independence, social inclusion and it is a source of a positive identity; similarly, working has positive social connotations as this is perceived as being productive (Skellern in Talbot et al., 2010; Stuart, 2006; Roulstone, 2004; Barnes, 1994).

Currently in Ireland, the rates of employment among disabled people are notably lower than the general population; in the same way, when employed, their earnings are lower than non-disabled workers (McDonnell, 2007; WHO, 2011). Figures from

the Census of Ireland (2006) support this statement, indicating that only 35% of people with disabilities between the ages of 25 and 64 are more likely to be employed against 73% of the general population (Watson & Nolan, 2011). Yet, as stated in the report of the World Health Organization (WHO, 2011), it is a global issue the fact that people with disabilities have higher rates of unemployment than persons without disability (p. 235). According to the Irish Centre of Statistics office (2012), in the last census 2.1% of the population (274,762 people) had a psychological or emotional condition. However, there are not specific employment rates as disability is defined differently across surveys and organisations.

### **1.6 Relevance of this study**

The inequality experienced by disabled people has been characterised by their opinions and their civil and human rights being ignored. There have been extreme differences in the experiences of people with and without disabilities in important aspects of life such as living accommodation and employment. Despite the implementation of new international and local legislation to counteract the effects of those unequal conditions experienced by disabled people for centuries, substantial differences still exist. Thus, it is necessary to understand their current circumstances in key aspects of their lives, adopting a phenomenological approach, where the voices of people with disabilities are taken as a main source of information. Therefore, it was identified a need to undertake research to include individuals with disabilities to inform of their realities in employment, community activities and to explore their experiences across the living accommodations available to them areas, so to evaluate advances in the national strategy and to bring to an end the long-held tradition of ignoring their voices.

## **1.7 Aims of this study**

To address the gap in the knowledge this study aims to:

- 1) explore the employment status and community activity amongst people with intellectual disability (ID) and mental health problems (MHP) in a sample of the Republic of Ireland through descriptive statistics;
- 2) identify the relation between being employed and community activity levels through inferential statistics; and
- 3) Explore the life experiences for those in employment situation, both, paid employment and voluntary work, across different types of accommodation available to them, through case study methodology.

Therefore, considering the complexity of the phenomenon, mixed methods was considered the best approach to address the aims of the study. This study adopted a phenomenological approach by focusing on the respondents' answers to questions regarding some aspects of their lives.

## **1.8 Structure of the dissertation**

This study includes five chapters. Beginning with this introduction, which provides an overview of the background and rationale of the study. Chapter two will review relevant literature in the area of the study: type of accommodation for people with disability, community living, employment, social inclusion and legislation and policy in both, the international and the Irish context. Chapter three outlines the research methodology and design; describing the sampling and data analysis procedures, as well as the theoretical perspective and ethical considerations for this study. Chapter four presents the key findings of this mixed methods study and it is divided in three sections corresponding to the research questions. Chapter five concludes this study by discussing the main findings in relation to the existing literature, as well as outlining the limitations of the study, future research recommendations and a reflection on the learning process of conducting the study.



## **1.9 Conclusion**

In summary, the literature suggests that independent living is often not a reality for people with disabilities. Furthermore, statistical records confirmed the low rates of employment amongst this group of the population. However, the impact of those numbers on the day to day lives of persons with disabilities and MHP, gain an authentic meaning when individual experiences are described by those affected. Yet, there are a scarce number of studies that covers the experiences of disabled people in employment across different living arrangements to give account of their life experiences from their own perspectives. It is in that gap of knowledge and approach that the aims of this study originated.

## **2. LITERATURE REVIEW**

### **2.1 Introduction**

The overall aims of this study are (1) to explore paid employment and voluntary work status in a sample of people with MHP and ID, (2) identify the relation between being employed and community activity levels and (3) to further explore the experiences of those in employment situations living in various types of living accommodations. The literature review includes studies relevant to the areas of: employment, community living and social inclusion of people with disabilities as a human right; so as to identify what lead to the aims earlier stated. The literature review was conducted using mainly electronic searching through databases (PsycINFO, Social Sciences Index, SciVerse, PubMed, ERIC and Google Scholar), using the following key words: independent living, community living, deinstitutionalisation, employment, voluntary work, social inclusion, disab\*, mental health conditions, intellectual disability, learning disability and United Nations Convention on the Rights of Persons with Disabilities. This was complemented with hand searching of relevant journals and books. There were not set any restrictions on time, so as to access all relevant information (earlier publications were included for background and context).

This chapter first explores the research available at both a global and national level, in relation to deinstitutionalization and salient features of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). It will identify the different types of accommodation where people with ID and MHP live and the differences between the characteristics and outcomes that had been identified in each setting through research. Secondly, it looks at previous studies on employment and social inclusion amongst people with ID and MHP. Finally it will conclude by identifying the gap in the literature which led to the aims of this study.

### **2.2 People with disability exercising their rights**

Although people with disabilities were protected by general human rights conventions, this did not stop the violation of many of their human rights (Harpur,

2012, p.1). Throughout history and around the world, persons with disabilities were treated as lesser human beings (Quinn, 2009). This was especially true for those with ID, as according to Mercier and Lecomte (2009), they were forgotten by movements working for the recognition of fundamental human rights.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the first international treaty to specifically address the rights of disabled people and it is considered the most advanced and complete document available containing their rights (WHO, 2011; Council of Europe, 2012; Ollerton & Horsfall, 2012, p. 619). The Convention includes in the term 'disable' "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 equal basis with others" (United Nations, 2006, p. 5). Therefore, the Convention adopts the social model perspective of disability, where 'disability' is placed in the barriers that the environment and society impose, hindering their full inclusion in society; rather than on the persons' impairments.

As highlighted by Bartlett (2009), the CRPD includes human rights contained in other human rights treaties. However, the Convention is set in principles that protect the equality, dignity, inclusion, independence and autonomy of people with disabilities. Moreover, people with disabilities actively participated on the outline of the CRPD; with this act their voices reached the international arena (Ollerton & Horsfall, 2012). From all the articles contained in the Convention, the following are of particular relevance to this sector of the population: the right to live independently and being included in the community (article 19); the right to personal mobility (article 20); the right to work on an equal basis with others (article 27); the right to participate in cultural life (article 30) and the right to be free of exploitation and abuse (article 16). For the purposes of this study, the articles related to living independently and employment will be further explored in the following sub-sections. (For full text of Articles 19 and 27 see Appendix I).

Harpur (2012) analyses the impact of the CRPD and suggests ways in which the Convention could direct genuine change. For instance, he states that the disability rights discourse promoted by the CRPD empowers them and their advocacy groups (p. 2). Yet, other authors are of the opinion that the CRPD has been analysed

mainly from a juridical approach by people with legal expertise and that 'civil society actors' should contribute to the interpretation of The Convention (Mladenov, 2013) in order to be analysed from a different perspective.

### **2.3 Living independently and being included in the community as a human right issue.**

Nations around the world had signed and ratified the CRPD and are moving towards de-institutionalisation and community living (Quinn, 2009). However, the transition appears to be a big challenge, even for the States which had ratified it, such is the case in Mexico where institutionalised persons experience high levels of cruelty and neglect (Rosenthal, Jehn & Galvan, 2011). Nevertheless, developed countries such as the UK, will need to adjust local policy in order to accomplish the exercise of the rights stipulated in the CRPD such as living independently (Bartlett, 2009). Overall, existing literature in this area suggests that although the CRPD has the potential to make a real change in the lives of disabled people, a number of issues need to be addressed in order to move from policy to implementation (Harpur, 2012; Lang et al. 2011). In the European context, as reviewed in the next section, there has been a marked emphasis in supporting the de-institutionalisations of disabled people in accordance to the CRPD.

#### **2.3.1 The right to living independently in the European and Irish context.**

The United Nations and the European Commission called for a firm commitment to de-institutionalization underlying that the right to live in community setting is closely linked with fundamental rights such as personal liberty, private and family life, and freedom from ill-treatment or punishment (Council of Europe, 2012). Furthermore, the EU has established the "European Disability Strategy 2010-2020" with the intent that people with disability in the EU enjoy their full rights and are being included in society.

In the Irish context, the State has signed the CRPD but not yet ratified it. Nonetheless, the State is compelled by the EU law to ensure the independence of people with disabilities and their participation in the community life (Art. 26 of the Charter of Fundamental Rights of the European Union). According to the Disability Federation of Ireland (2013), disability issues are at the centre of Ireland's social policy agenda and this new direction is emphasised by the '*National Disability Strategy 2006-2016*', '*Towards 2016*' and the '*National Housing Strategy for People with Disability 2011-2016*', the latter endeavours closing congregated settings and moving 'residents' to community-based settings by 2016. Furthermore, the "*National Disability Strategy Implementation Plan 2013-2016*" intends to focus efforts on ratifying the CRPD and to strengthen community capacity to integrate and support people with disabilities to live independent lives, with greater choice and control (National Disability Authority n.d); planning to achieve this within the context of the CRPD, in particular the Article 19. Just over a decade ago Reinders noted that rights-based approaches are an important development and they "open doors but fail to change what happens when people walk through them" (Reinders, 1997 in Clegg et al., 2008, p. 92). Although this was stated before the CRPD, it could also be applied to it. For instance, in relation to independent living, if the adequate support is not provided to people with disabilities before and during the transition, it might leave disabled people without knowing how to cope with the change.

## **2.4 Types of accommodation**

A growing number of authors have defined the types of accommodation where people with disabilities live, yet struggle to reach an agreed categorization due to the differences in domestic policies and the services provided (Felce & Emerson, 2001). However, it is possible to identify the most common ones:

- a) Institutions/congregated settings: "any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size" (European Coalition for Community

Living, 2013). Common characteristics of institutions usually include large size, different architecture than the rest of the houses in the area, removal of personal items or signs of individuality (depersonalisation), limited daily activities or interaction with the community and many people sharing the same unit or bedroom (Mansell & Beadle-Brown, 2010, p. 105).

- b) Clustered housing: “a number of living units forming a separate community from the surrounding population” (Mansell & Beadle-Brown, 2009, p. 314). Two examples of this are village communities and residential campuses. In a wider scheme, these are also considered congregated settings because although less people are sharing the facilities, they still share institutional like features.
- c) Group homes: it is a group of apartments or houses of the same type, located among ordinary housing in groups of approximately six persons (Mansell & Beadle-Brown, 2009; McConkey, 2007).
- d) Family homes: they remain living with a relative, whom in the majority of the cases provides care/support to the person with disabilities (McConkey et al, 2013).
- e) Personalised arrangements: are characterised by more individualised attention, informal relationships and person-centeredness (Chilvers, McDonald & Hayes, 2010). These typically include accommodation in ordinary houses or apartments, either living alone or sharing with people they have chosen. In these types of settings, usually, the person with disability has the option to decide the location of their house/apartment and have opportunities to interact within the community (McConkey et al, 2013).

There is a growing body of research documenting the benefits of community-based services over institutions. For instance, community participation and the quality of support provided are better in community-based settings (Mansell & Beadle-Brown, 2010; McConkey, 2010). Similarly, other areas are influenced positively, such as social integration and community participation (Ager et al., 2001; Emerson, 2004). Contrarily, other authors like Cox and Pearson (1994) state that people with ID have benefited from living in small group settings among others with similar needs as they have more security; arguing that because they are in contact with other people, they are not isolated. In statements like that, there were critics that lead to the theme of choice, as those living in institutions (larger or small), had not chosen the people with whom they

share facilities. On the contrary, people who live in community-based settings reported to have more choices, better self-determination, better quality of life, and satisfaction (Stancliffe & Keane, 2000; Stancliffe, 2001; Martinez-Leal et al., 2012; McConkey, 2007 & 2010; Chowdhury & Benson, 2011; O'Brian et al., 2001).

Others authors maintain that moving from congregated to personalised settings may cause persons with disability an intense feeling of fear because they do not know what to expect from the new environment (Veitch, Bray, & Ross, 2003). That might be true for many people in those circumstances who had considered institutions their 'home' and where staff has been making decisions for them for years. To put this in perspective, in Ireland around 75% of residents in congregated settings have been living there for over 15 years (HSE, 2011); moving them out from those settings, will indeed, be challenging for each person. However, other authors argue that if the correct level of support, training and life skills are provided; the level of stress can be greatly reduced (McConkey, 2010 & Veitch, Bray, & Ross, 2003). In this regard, Johnson (2005) notes that the emotions and feeling experienced by disabled people who move from institutions to the community are neglected and often not well documented in the literature (p.149).

Regarding people living in the family home, researchers have found mixed outcomes from the environment. On the one hand, people with disabilities are benefitting from the community-based life style; but on the other, they may experience isolation and some studies have reported mixed feelings of happiness/loneliness (Weber & Fritsch, 1999 in O'Rourke et al., 2004). In many cases, parents of children with disabilities, in their purpose to facilitate care and protection to their children, unintentionally limit their social, psychological or/and physical development (Sanders, 2006; Morris, 1993). In the early 1990's Morris stated that for some young disabled, going to residential care was considered an alternative to the family home in cases where the person experienced 'significant constraints' especially when the world outside the home provides little opportunity for independence and, indeed, nurtures dependency (Morris, 1993). Wehmeyer et al. (2005) found that people with ID who were living with relatives or independently had more self-determination than those living in congregated settings.

Wehmeyer et al. (2005) in their definition of self-determination, include that people with disabilities have four characteristics: acting autonomously, self-regulated behaviour, initiate and respond to events in a psychological empowered manner, and the person acting in a self-realizing manner. Wehmeyer (1998) in an earlier work, noted that the term self-determination had been wrongly conceptualised as: 'having full control'; 'self-sufficiency'; 'independent performance' and so on; causing the collective misperception that this term does not apply to people with significant disabilities. Therefore self-determination is closely linked with the support provided to make choices, as some people, due to the characteristics of their impairments require assistance in this regard.

Similarly, the concept of autonomy has received special attention in disability studies literature. In relation to living in institutions, the literature suggests that the system in those settings threatens the fundamental right to autonomy (Boyle, 2008), while welfare payments and the lack of real employment opportunities maintain them dependant to the state, obstructing their personal autonomy (Oliver, 1996). Thus, people with disabilities who live in the community are expected to be more autonomous (Wullink et al., 2009, p. 817). The Council of Europe Commissioner states that 'choice' and 'autonomy' can be identified in the article 19 of the CRPD as it aims to neutralise isolation and loss of control over their lives (Council of Europe, 2013).

In summary, although some authors believe that living in institutions is beneficial in some ways for people with disabilities, most of the research provides evidence of the greater benefits from living in community-based settings over institutions/congregated settings.

## **2.5 Social inclusion**

There is a growing body of research in relation to social inclusion of persons with disabilities. Social inclusion addresses values associated with human rights, citizenship, economic and social justice, gender, ethnicity, poverty, and sexuality as well as disability (Richardson, 2007, p.71). Bellani and D'Ambrosio (2011), define social inclusion as the ability of an individual to participate in political, economic and



social activities within their community. In other words, a person is socially included when they exert their right to vote, to work, and to participate in an activity of their interest. This, as stated by some authors, had been taken for granted by able-body persons, but it is not a reality for the majority of people with disabilities. Therefore, social inclusion is a complex concept (Wright & Stickley, 2013; Richardson, 2007) and according to Sen (1998) it can be affected directly by social and economic problems such as low education attainment; poor housing, poverty and unemployment. In a recent study those barriers noted by Sen (1998) were also mentioned by people with disabilities as major barriers to social inclusion. They identified: personal abilities and skills (e.g. poor literacy or numerical skills); the role of support staff (e.g. not allowing them to go out alone); the community (e.g. not enough activities offered) and the location of the place they live (e.g. lack of accessible transport) (Abbott & McConkey, 2006).

These findings are of particular importance, as with them it is possible to see what social inclusion for people with disabilities is and what is preventing them from experience it on their daily lives. Another study in which the perspectives of people with disabilities were included is Hall's (2005), identifying key factors for social inclusion: being accepted and recognized as an individual beyond the disability; being in contact with family, friends and other people; being involved in recreation, leisure and other social activities; having appropriate living accommodation, employment and adequate support. Cobigo and Stuart (2010) identify four tools to promote social inclusion for persons with MHP: legislation; community support services; anti-stigma and antidiscrimination initiatives and system monitoring and evaluation. Here, an important barrier to social inclusion is stigma.

Stigma and discrimination affects the following; affecting people's dignity, their civil, political, economic, social status, their cultural rights, limiting their employment opportunities, affecting their family relationships and friendships (Guimon, 2010, p.23; Meij & Heijnders, 2004). Scior (2011) suggests that the general public lacks awareness and understanding of the label 'intellectual disability' and usually undervalue the capabilities of people under such a category. She further states that "Lay people want greater social distance from people with intellectual disabilities than those with physical disabilities, but individuals with severe mental health problems appear to be even more stigmatised" (Scior, 2011, p. 2178). Assertions like

this are important for the understanding of stereotypes that society have with regards to people with ID and MHP. In Ireland, in a recent survey it was noted the increasing negative public attitudes towards people with disabilities (NDA, 2012).

In a recent work Lysaght, Cobigo and Hamilton (2012) reviewed literature on employment and social inclusion and they noted that some authors use the terms 'social inclusion', 'social participation', 'social integration' and 'community participation' as part of the same aspect of achieving well-being in the social aspect of their lives. However, there are differences between these concepts. For instance, community participation refers to full engagement in activities such as education, employment and recreation; while social inclusion is, as reviewed above, a more complex concept.

In relation to community activity, previous research suggests that people with disabilities who live in small and individualised environments are more likely to engage in community activities and to have wider social networks than those living in congregated settings (Emerson et al, 2011; McConkey et al. 2007). Fincher and Iveson (2008) talk about 'convivial encounter', which refers to engaging in any activity where the people with disability go from being 'the disabled person' to 'the library user' or 'the museum visitor'. They argue that those types of activities are often not considered by community services for people with disabilities, although they could be exceptional opportunities for them to get the use of community services and enlarge their networks while participating in the community.

In the European context, the theme of social inclusion/exclusion is one of the key challenges and is also an issue of political debate (Giambona & Vassago, 2013); in Ireland '*The National Action Plan for Social Inclusion 2007-2016*', has been implemented, aiming to facilitate opportunities for people with disabilities in Ireland to be socially included. Yet people with disabilities are still excluded from society in a wide range of sectors and activities (NDA, 2005). Therefore, the literature suggest that both, independent living and social inclusion are portrayed as major aims to achieve in the near future, but their nature denotes a complexity that demand cautious and comprehensive planning in order to be achieved. Bigby and Fyffe, 2009 state that if those aspects, jointly with the individual requirements are not taken into consideration, any aspirations of social integration and participation will be hollow.

## 2.6 Employment

For people with disabilities, being employed has distinct benefits which can only be achieved while working such as time management, a sense of responsibility and increased communication skills (Owen et al., 2005). This is also meaningful at a personal level by promoting their self-esteem, identity and improving their confidence and independence.

Contemporary research had documented the high rates of unemployment among disabled people and had sought to identify the causes of such circumstances. In the '*World Report of Disability*' it is noted that there are many possible explanations, namely the lack of access to education and training; the nature of the workplace; employers' perceptions of disability and also the individuals' low self-expectations (WHO, 2011). Similarly it is recognised that, typically, this group of the population experience poverty, which, in part, is due to the low employment rates and the scarce opportunities to join the workforce (Lysaght, Cobigo & Hamilton, 2012) and when hired they are not well paid (Oliver, Sapey & Thomas, 2012). Consequently, when people are denied the opportunity of employment, it has economic, social and psychological repercussions on their lives (Barnes, 1994). Wistow and Schneider (2003) studied in the UK the perceptions of employment among persons with ID and they concluded that the majority of those employed had jobs characterised by poor working conditions; low wages; limited opportunities for advancement; and limited choices regarding their schedules. Those negatives issues lead to feelings of isolation and being unhappy in their jobs. Similarly, people with MHP had experienced comparable restrictions to being included in the labour market, underestimating their abilities, interests and aspirations (Secker, Grove & Seebohm, 2001).

Further studies explored the reasons reported by employers for not hiring or retaining workers with disabilities; they discovered discriminatory practices such as: employers had a lack of knowledge of disability and how to accommodate their needs; they also had concerns over costs; fear of legal liability and they were concerned about reactions from co-workers (Kaye, Jans & Jones, 2011; Paludi, DeSouza & Dood, 2011). Thus, there are numerous barriers also for the integration of people with ID and MHP to the workforce. Shah & Priestley (2011) state that

people with disabilities in older generations were assisted by family members to find employment. In the UK context, Oliver, Sapey and Thomas (2012) argue that when employment is the main goal of the person supported, social workers should not be in a dilemma of whether to assist or not a person with disabilities to get into the workforce, rather they 'should take a more active role' as part of their task; acting as advocates rather than delegate it to contractors or agencies.

The European Union Agency for Fundamental Rights (2012) published a report of the daily experiences of people with ID and MHP in nine European countries living independently. In the area of employment people with mental health problems had difficulties to find employment because of prejudice from employers and due their low educational attainments (because some of the mental health problems start in the adolescence, affecting their studies). In many cases, they engage in sheltered workshops, which, as seen in the introductory chapter, this reinforces stigmatisation and isolation, while hinders their enrolment in the labour market.

## **2.7 Identifying the area of research**

Accommodating people with ID and MHP in personalised settings/independent living has recently captured the attention of researchers and social policy makers; in part, guided by the *UN Convention on the Rights for Persons with Disability*, (CRPD), 2006. It has been well documented how moving disabled people from congregated settings/institutions has benefited many aspects of their lives. However, little research has been conducted, in Ireland, in relation to what life is like for people with disabilities who are in employment situations across the various settings where they live. Therefore, this study aims to address this gap by studying in depth their experiences, from their own perspectives and distinguishing the differences across those settings.

## **2.8 Conclusions**

This chapter provided a brief introduction to the body of research on employment and social inclusion of people with disabilities and about the various aspects of the settings where they live. While the sections above are not exhaustive due to the complexity of the themes, this chapter provided a relevant introduction to the areas. Likewise, it has covered the CRPD in general and in particular the Article 19. Finally, it identified a gap in the knowledge, which this study seeks to address.

## **3. RESEARCH METHODOLOGY**

### **3.1 Introduction**

This chapter begins by outlining the aims of the study, stating the research questions and providing a definition of key terms. Additionally, it follows an outline of the research method and design; sampling process; sample characteristics and data collection and analysis. Finally this chapter concludes with the discussion of rigour in qualitative research and ethical considerations.

### **3.2 Aim and Research Questions**

This study conducted a secondary analysis on data collected as part of a larger longitudinal study in the Republic of Ireland, whose aim was to evaluate personalised support to individuals with both physical (P) and intellectual disabilities (ID), as well as mental health problems (MHP) of people who were moving to a more personalised setting. The purpose of this mixed methods study was (1) to explore paid employment and voluntary work status in a sample of people with MHP and ID; (2) to identify the relationship between being employed and community activity levels and (3) to further explore the experiences of those in employment situations living in various types of living accommodations. Due the complexity of such phenomenon, mixed methods was considered the right approach to address the research questions. Thus, this mixed methods study had two phases; quantitative, followed by a qualitative phase.

Two research questions guided the first phase of this mixed methods research study.

1. What is the employment situation of people with ID and MHP?
  - 1a. What is the paid employment situation amongst people with ID and MHP?
  - 1b. What is the voluntary work situation of people with ID and MHP?
  
2. Is there a relation between community activity levels and employment status?

The qualitative phase of this study aimed to answer to the following research question:

1. What are the life experiences of people with ID and MHP who are in employment situation across the various types of accommodation where they live ('personalised settings', 'congregated settings' and 'family home')?

### **3.3 Definition of terms**

This research study included terms that might acquire different meanings or interpretations. For the purposes of this study, those terms are defined below:

Definitions of living accommodations were taken from the wider study, which is not yet published.

*Employment* is defined as the condition of having paid work. However, because it also denotes an activity to which ones dedicates time, in the second phase of this study (qualitative), people working included both, people in paid employment and those engaged in voluntary work. However, emphasis on differentiating both is made at all times.

*Community activity* refers to mainstream activities done in the community which in this study was measured through eight criteria: 1) gone to pub, café or restaurant; 2) played sports, swimming or fitness classes; 3) attended church or mass; 4) gone to the cinema, concerts or sports event; 5) social club- indoor games and crafts; 6) dances, parties, celebrations; 7) short courses such as computer classes; and 8) any other things done.

*Congregated setting* typically includes campus accommodation of separate bungalows and houses on a shared site as well as hospitals ward-like settings.

*Personalised settings* typically include accommodation in ordinary houses or apartments either living alone or sharing with people they have chosen. In these settings, usually the person with disability decides the location, the people with whom they live and the furnishing.

*Family Home* refers to the parents' or sibling's place, where people with disability live, usually at the care of family members.

*Group home* refers to ordinary housing (apartment or houses) of the same type, scattered throughout residential neighbourhoods amongst the rest of the population. They are usually shared by up to six persons with disability or mental health condition (McConkey et al., 2013)

### **3.4 Research Methods and Design**

Mixed methods is 'research in which the enquirer or investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of study' (Tashakkori & Creswell, 2007b, p.4).

A mixed method approach was selected because the combination of quantitative and qualitative design and the final triangulation of findings, which offers a deeper understanding of the phenomenon studied (Tashakkori & Creswell, 2007; O'Cathain, Murphy & Nicholl, 2008; Plano-Clark & Creswell, 2008).

This mixed methods study was sequential and explanatory in design as the quantitative results were used to guide the purposeful sampling of participants for the qualitative phase of this study (Tashakkori & Teddlie, 2003). See Appendix II for a visual diagram of the mixed-methods design.

The quantitative phase consisted of descriptive and inferential statistics in relation to employment; voluntary work and community activities across the different types of accommodation available to people with ID and MHP. The qualitative phase was addressed through case study methodology, which consisted of three case studies corresponding to the type of accommodations: personalised settings, congregated settings and the family home.



### **3.5 Theoretical perspective**

This mixed methods study used a phenomenological approach by focusing on the respondents' answers to questions regarding some aspects of their lives. According to Creswell (1994), the aim of phenomenology is to “determine what an experience means for the person who has had the experience and is able to provide a comprehensive description of it” (p. 53). This involves the exploration of the “structures of consciousness in human experiences” (Creswell, 1998, p. 51). Thus, the aim of phenomenology is compatible with the aims of the present study. Therefore, it was chosen as a theoretical perspective to conduct this study; because here, the voices of people with ID and MHP were the main source of information in order to understand their experiences.

Although there is not a universal definition of disability, the perspective of disability has changed in recent times. Moving from a traditional medical perspective, where the impairment was understood to disable the individual, to the social model of disability which takes into account the conceptualization of disability as a result of disabling practices and attitudinal barriers of the environment and the wider society; excluding them from participating in mainstream activities (Barnes, 1994). Following a social model approach of disability throughout the study, from the introduction to the discussion chapter; attention in this study is paid to external barriers that disable the individual.

Traditionally, the voices of persons with disability have been silenced through institutionalisation and other disempowering practices. The intention of the researcher, from the beginning of this study, was that of giving a voice to people with disability primarily following a phenomenological approach linking this to the social model of disability. The voice of the person with disability is prioritised at all times throughout this study. However, in some cases the persons with disability were not interviewed due to circumstances out of control to the researcher. When this occurred, their voices and experiences were explored through their relatives or/and key workers.

### **3.6 Data Collection Methods**

This study conducted a secondary analysis, from data collected by nine research assistants for 'the wider study'. Data was gathered from face to face interviews at three points in time:

Interview 1: from October-March, 2012; Interview 2: May-July, 2012; and Interview 3: November, 2012-May, 2013.

Access to raw data (audio-files and database in SPSS programme, version 20) was granted by the Coordinator of the MSc. in Disability Studies, Dr. Ederne Garcia-Iriarte, with the consent of the lead researcher Dr. Roy McConkey. The use of such data was approved by the Ethics Committee of the School of Social Work and Social Policy, Trinity College Dublin. It is worth noting that access to this secondary data allowed the researcher to work with a sample that would have been otherwise inaccessible. Likewise the size of the sample would have not been reachable within the short period of time available to complete this study (O'Leary, 2010).

The first phase/strand of this study involved quantitative data collection; data was collected through pro-forma and rating scales and answers were coded and organised in a SPSS data set. This dataset was provided by the lead researcher of the wider study via e-mail (ethical considerations will be approached in another section).

The second strand involved qualitative data collected through semi structured interviews (Appendix III), aiming to reach more extensive material (Yin, 2012, p. 12). Answers were audio recorded while consent for audio recording the interviews was given to the interviewers orally in each session prior to participation. Interviews ranged from seven minutes to just over one hour in length. Audio-files were provided also by the lead research via DropBox (ethical considerations will be approached in another section).

### 3.7 Population and sample

The selection of the population and sample was done by researchers from the wider study, mentioned earlier in this chapter, which is referred to as 'the Genio project' for being a project funded by Genio Trust, an Irish non-profit organisation which provides funding for projects of social nature. Selection of the sample in the wider study was conducted through services that had received a grant from Genio-Trust. Those services nominated individuals and some individuals nominated themselves to take part in 'the Genio project'. Research assistants recruited them for the study; obtaining informed consent prior to participation in the study (McConkey et al, 2013).

Generally, mixed methods research employs two types of sample sizes. Quantitative sample is usually larger than the qualitative sample (Teddlie & Tashakkori, 2009). As mentioned by Teddlie and Tashakkori (2009), in mixed methods research, it is more common that the qualitative phase follows the quantitative and it is more likely that the information generated in the quantitative phase guides the selection of participants with very particular characteristics for the qualitative phase of the study (p. 189). In this study, the sample for the quantitative was larger and preceded the qualitative phase.

The sample population for this study consisted of persons with ID and persons with MHP in both phases of the research. The rationale behind this selection was that both groups (persons with MHP and ID) are likely to face similar barriers to full inclusion, participation in activities and employment (FRA, 2013). Furthermore, similarly to 'the Genio Project', this study involved three groups of stakeholders; the people with ID and MHP, their family members and their key workers. Two phases of sample procedures were employed in order to answer the research questions – the quantitative phase and the qualitative phase.

#### *Quantitative sample:*

For this phase of the study, the population consisted of 105 participants with intellectual disability, 58 females and 47 males, with an average age of 47 years (DS=15.1, Range=17-74). (This is the entire sample of 'the Genio project' of people with ID and MHP). There were 60 participants with mental health conditions, 40 of

them males and 20 females, with an average age of 42 years (DS 11, Range= 23-64). (See Table 3.1)

Table 3.1

*Demographic information of participants in the quantitative phase*

| Type of disability      | Number of participants | Gender |       | Age  |      |        |       |
|-------------------------|------------------------|--------|-------|------|------|--------|-------|
|                         |                        | Female | Male  | Mean | DS   | Median | Range |
| Intellectual disability | n=105                  | n=58   | n=47  | 46.7 | 15.1 | 47.7   | 17-74 |
|                         |                        | 55.2%  | 44.8% |      |      |        |       |
| Mental health condition | n=60                   | n=20   | n=40  | 42.3 | 11.0 | 41.5   | 23-64 |
|                         |                        | 33.3%  | 66.7% |      |      |        |       |

*Qualitative sample:*

The sample for the qualitative phase was identified subsequent from the quantitative phase. The aim of the purposeful sampling is to select information-rich cases whose study will illuminate the questions under study (Patton, 2002, p.46). This was possible after the quantitative phase, identifying people who were employed or engaged in voluntary work in each group of disability (ID and MHP), followed by identifying those in each living accommodation.

Sample population for the qualitative phase consisted of nine people, five females and four males, aged between 20 and 61 years of age. Of the nine people, seven were persons with ID, while two were persons with MHP. At the time of the interviews (from November 2012 to May 2013) participants were living in three different types of accommodation; four in personalised settings, three in congregated settings and two in the family home. Note that participants who in the quantitative phase were identified as moving from one setting to another (e.g. from congregated to personalised settings or from congregated settings to group homes), in this phase of the study are allocated in personalised settings or congregated settings respectively as this phase of the study focused on the third interview, where 'moves' to settings had already taken place.

As mentioned before, three groups of stakeholders formed the case study, but only the person supported is called throughout this study 'the participant'; while persons

with ID or MHP, their relatives and their key workers are called ‘the informants’. In total, there were 21 informants; eight persons with disabilities, five relatives and eight key workers (See Table 3.2). Note that only one participant (Maureen) was not interviewed, and her experiences living in congregated settings are noted from the perspectives of her relative and her key worker.

Table 3.2

*Demographic information of participants in the qualitative phase*

| TYPE OF ACCOMMODATION | NAME OF PEOPLE* | GENDER         | TYPE OF DISABILITY | AGE             | 3 <sup>rd</sup> interview |          |            |
|-----------------------|-----------------|----------------|--------------------|-----------------|---------------------------|----------|------------|
|                       |                 |                |                    |                 | PERSON WITH DISABILITY    | RELATIVE | KEY WORKER |
| Personalised setting  | Patricia        | Female         | ID                 | 51              | 1                         |          | 1          |
|                       | Tom             | Male           | ID                 | 54              | 1                         |          | 1          |
|                       | Lucy            | Female         | ID                 | 53              | 1                         |          | 1          |
|                       | Jack            | Male           | MHP                | 57              | 1                         |          |            |
| Congregated setting   | Janet           | Female         | ID                 | 61              | 1                         | 1        | 1          |
|                       | Paul            | Male           | MHP                | 61              | 1                         | 1        | 1          |
|                       | Maureen         | Female         | ID                 | 38              |                           | 1        | 1          |
| Family Home           | Robert          | Male           | ID                 | 24              | 1                         | 1        | 1          |
|                       | Lisa            | Female         | ID                 | 20              | 1                         | 1        | 1          |
| TOTAL                 |                 | F (5)<br>M (4) | ID (7)<br>MHP (2)  | average<br>46.5 | P (8)                     | R (5)    | KW (8)     |

\* Names are pseudonyms as all data have been anonymised.

Last three columns indicate who provided information by case.

### 3.8 Data analysis

Mixed methods research includes the collection and analysis of quantitative and qualitative data (Edmonds & Kennedy, 2013; Creswell, 2008). This study followed a similar approach.

### 3.8.1 Quantitative Analysis

Research questions corresponding to the quantitative phase exploring paid work and voluntary work situations amongst both groups, people with ID and people with MHP in each type of accommodation were addressed using quantitative analysis methods (Teddlie & Tashakkori, 2009). First, descriptive statistics were used to describe and summarize the characteristics of the sample in employment and voluntary work variables. Those variables were analysed across groups (ID and MHP) and across time (1<sup>st</sup> and 3<sup>rd</sup> interview). Second, inferential statistics were generated after descriptive results (Teddlie & Tashakkori, 2009). Inferential statistics (independent samples t-test) was used to explore the relationships between two variables: paid employment and community activity (O'Leary, 2010). This was performed with SPSS for Windows, version 20; when  $P < .05$  was considered significant.

Employment was measured by asking: 'Are you in paid employment?' The possible answers were Yes/No. (See Appendix IV)

Community activity was measured by asking questions related to activities undertaken (or not) by people with disabilities (with ID and MHP) in the four weeks prior the interview outside the disability/mental health services (see Appendix IV). In other words, activities that people got engaged (on their own, with friends, staff or a family member) in their community. This was measured through eight criteria: 1) gone to pub, café or restaurant; 2) played sports, swimming or fitness classes; 3) attended church or mass; 4) gone to the cinema, concerts or sports event; 5) social club- indoor games and crafts; 6) dances, parties, celebrations; 7) short courses such as computer classes; and 8) any other things you have done?

In the wider project answers were rated according to whether the activities were undertaken or not and with whom they were undertaken with (0, not done; 1, by self; 2, with friends; 3, with staff; 4, with family and 5, more than one category). However, for the purposes of this study, the answer 'not done' was recoded to a value of 0; whereas if the activity was done it was recoded to a value of 1 (0, no; 1, yes). Finally, a summary measure of community activity was derived by summing the responses across items (ranging from 0- not done to 8-all activities done). Therefore, higher scores represented higher levels of activity in the community.

### 3.8.2 Qualitative Analysis

Research question three: 'What are the life experiences of people with ID and MHP who are in employment situation across the various types of accommodation where they live ('personalised settings', 'congregated settings' and 'family home')?' was addressed through case study methodology. These case studies were three in total corresponding to the various types of living accommodation. Although data collected from the three points in time was available from the longitudinal wider study, the researcher decided to focus on the last data intake (November 2012- May 2013) as it reflected the most up-to-date information on each participant.

Data analysis in the qualitative phase consisted of three stages: Transcription, coding and thematic analysis. The first stage of the data analysis was to transcribe verbatim (see Appendix V) the audio-files of semi-structured interviews (Saldaña, 2013, Matthews & Ross, 2010; Patton, 2002). Once the researcher completed all the transcripts, time was taken to become 'immersed' in the data (Langley, 1999) by reading each transcript several times. Data was analysed using content analysis (Patton, 2002). While reading the transcripts analytically, the initial list of possible codes began to emerge (Manen, 1990). In the early stages of the analysis open line-by-line verbatim coding was undertaken and words and phrases that were considered a source of information about the lives of people with disabilities were underlined with different colours. Subsequently more thorough codes were identified and a codebook was developed; containing three elements: code, brief definition and examples (Appendix VI). Thus, codebook was data driven rather than theory driven. Codes and codebook were constantly revised during the analysis, as the researcher gained a better insight into the data collected in the interviews (DeCuir et al. 2011; Patton, 2002). Quotations from transcripts were selected and are provided to be representative of the experiences of the persons with ID and MH, as are those of their key workers and relatives. Once categories and themes were identified in each case study, a cross-case study process took place. This consisted of comparing categories, themes and subthemes across the three case studies.

Finally, qualitative and quantitative findings were not integrated during the data analysis, but at the stage of interpretation and discussion. This was achieved

through triangulation where results from the quantitative and qualitative were integrated (Teddlie & Tashakkori, 2009).

### **3.9 Rigour**

As stated by Teddlie and Tachakkori (2009), data quality in mixed methods research is “determined by standards of quality in the quantitative and the qualitative strands”. However, a strategy that is often used in assessing the overall quality of data in mixed methods research is data triangulation.

In this section, it is necessary to note that in the quantitative phase of this study, the validity and reliability were not tested. Descriptive statistics are presented as inferential statistics. However, the results of the inferential statistics should be taken cautiously as the nature of this quantitative phase is only exploratory. That stage of this study sought only to explore the relation between employment and community activity.

The following strategies were employed in this study to ensure trustworthiness of the quality of data and the credibility of the research findings from the qualitative phase of study:

*Triangulation techniques*; triangulation of methods, using quantitative and qualitative methods were employed to investigate the phenomenon under study.

*Triangulation of sources*; persons with ID and MH, their relatives and their key worker were interviewed in order to have different perspectives to the phenomenon studied aiming to strengthen the study’s findings. (Denzin & Lincoln, 1998; Yin, 2012).

*Peer debriefing*: involved feedback provided by a neutral peer (Lincoln & Guba, 1985). For this study, a former student with an interest in Disability Studies, conducting her own qualitative research served in the capacity of peer debriefer. All the details of the research were supplied to her and she made minor comments in relation to the coding process, suggesting to make minor changes or to include themes in a wider category. Those comments were discussed in a professional and



ethical manner and an agreement was reached. After two sessions she considered that the codes assigned were adequate.

### **3.10 Limitations**

This study had some limitations. First and foremost it analyses secondary data. Thus, the limitations revolved around the lack of control in generating the data, which is linked to how data was collected and recorded such as the sampling strategy, the interviewing process, the items contained in questionnaires, and so forth. Furthermore, data was collected by a team of nine research assistants, which leads to different styles of collecting data during the interviewing process.

In respect to data collection, the interviewer may not have had experience interviewing people with intellectual disability; consequently the way they asked questions might have been intelligible to them (Butterfield & Arthur, 1995). For instance, this was recognised by one of the key workers in one of the recorded interviews. The researcher feels that, in some cases, if the interviewer would have asked questions in an accessible way to people with ID, they would have answered more questions and provided richer information (Perry, 2004). This is reflected in the finding sections where the amount of quotations from some participants is fewer.

Another limitation is related to the sampling methods in which the wider study population was deliberately selected and it is only representative of the services that obtained funding from Genio Trust for their projects. To minimise the limitations, it was requested from the research leader of the 'Genio project' as much information as possible about the collection of the data and the population (Henn, Weinstein and Foard, 2010). It is worth noting that, despite the limitations, access to this secondary data allowed the researcher to work with a sample that would have been otherwise inaccessible. Likewise the size of the sample would have not been reachable within the short period of time available to complete this study (O'Leary, 2010).

Another limitation is in relation to the research design as noted by Plano-Clark and Cresswell (2011) who state that using an explanatory design 'requires a lengthy amount of time for implementing the two phases' (p.85). Therefore, due to time constraints for the completion of this study, both, the quantitative and qualitative did

not reach the depth that the researcher planned before. And as stated earlier, the results of the inferential statistics on the quantitative phase should be taken cautiously as are of an exploratory nature.

### **3.11 Ethical considerations**

Ethical approval for this study was granted on the April 25<sup>th</sup>, 2013 by the Research Ethical Approval Committee (REAC) at School of Social Work and Social Policy, Trinity College Dublin (Appendix VII). The REAC requested the signing of an Confidentiality Agreement between the researcher and Dr. Garcia Iriarte; this requirement was fulfilled (Appendix VIII). Confidentiality measures were upheld by anonymising transcripts, assigning pseudonyms and storing audio-files in password-protected files on the researcher's personal laptop.

Data set on SPSS (version 20) was provided via email, the email was deleted and the data set was saved in a password-protected file. Regarding audio-files, the researcher had access to them through Drop Box, those files were deleted once they were saved in a password-protected file. Once audio-files were transcribed verbatim, they were given to the Coordinator of the MSc. in Disability Studies, Dr. Edurne Garcia-Iriarte, in Microsoft word format with the original code number and with names omitted or pseudonyms where necessary.

In relation to the policy of data storage, electronic data including SPSS database, audio-files and verbatim transcripts will be kept for a maximum of two years following the completion of this study on password-protected files on the researcher's personal laptop. These procedures were upheld in accordance with the Data Protection Guidelines on Research in the Health Sector 2007 and The Trinity College's Policy on Good Research Practice, 2009.

### **3.12 Conclusions**

This chapter has outlined key elements of this mixed methods study. Using both, quantitative and qualitative approaches, this study had the elements to explore in depth the complex experiences of people with ID and MHP who are employed and living in diverse settings. Chapter 4 outlines the main findings of this mixed methods study.

## 4. FINDINGS

### 4.1 Introduction

This study is aimed at answering the following research questions (RQ):

1. What is the employment situation of people with ID and MHP?
  - 1a. What is the paid employment situation amongst people with ID and MHP?
  - 1b. What is the voluntary work situation of people with ID and MHP?
2. Is there a relationship between community activity levels and employment status?
3. What are the life experiences of people with ID and MHP who are in employment situations across the various types of accommodation where they live ('personalised settings', 'congregated settings' and 'family home')?

The following sections contain findings to the RQs. RQ1 corresponds to the sections on employment and voluntary work, RQ2 to the section on community activity and RQ3 to the three case studies and the cross-case analysis. Finally this chapter concludes integrating findings from three RQ and a conclusion is provided.

### 4.2. Employment Findings

This section answers RQ 1a. What is the paid employment situation amongst people with ID and MHP?

The employment situation was analysed for both people with ID and those with MHP at two points in time (Time 1 (T1) and Time 3 (T3)). T1 refers to the first data uplift (October 2011-March 2012) while T3 refers to the third and last data uplift (November 2012-May 2013). Data indicates that at T1 and T3 the vast majority of the samples were unemployed. At T1, 91.5% of people with MHP and 77.9% of those with ID reported being unemployed. These numbers were similar at T3 (95.7%

and 77.7% respectively). These results suggest that those with ID have slightly lower rates of employment than those with MHP (see Table 4.1).

Table 4.1  
*Employment/Unemployment situation by type of disability at T1 and T3*

| Type of disability      |   | Time 1   |            |       | Time 3   |            |       |
|-------------------------|---|----------|------------|-------|----------|------------|-------|
|                         |   | Employed | Unemployed | Total | Employed | Unemployed | Total |
| Intellectual disability | n | 23       | 81         | 104   | 21       | 73         | 94    |
|                         | % | 22.1%    | 77.9%      | 100%  | 22.3%    | 77.7%      | 100%  |
| Mental health problems  | n | 5        | 54         | 59    | 2        | 44         | 46    |
|                         | % | 8.5%     | 91.5%      | 100%  | 4.3%     | 95.7%      | 100%  |
| Total (n=)              |   | 28       | 135        | 163   | 23       | 117        | 140   |

NB Table reports only data of those who responded to the question 'are you in paid employment?'

#### 4.2.1 Intellectual Disability

Table 4.2 shows the employment/unemployment situation at T3 for participants with an intellectual disability by type of accommodation. T3 has been selected as it is the last data intake, which means that moves from one setting to another have taken place for some of the participants. There were a total of 89 people with ID who answered the question 'are you in paid employment?' Data indicates that only those living in personalised settings and in their family home were employed, with employment rates of 36% and 53% respectively. Conversely unemployment was at 100% by those who were living in congregated settings (n=24), by those who moved from congregated to group home (n=21) and those who moved from congregated to personalised settings (n=5).

Table 4.2

*Employment/unemployment situation for participants with intellectual disability by accommodation at T3*

| Type of accommodation  |       | Employed | Unemployed | Total |
|--|-------|----------|------------|-------|
| Personalised Setting at T1 and T3                            | n     | 8        | 14         | 22    |
|  | %     | 36.4%    | 63.6%      | 100%  |
| Congregated Setting at T1 and T3                             | n     | 0        | 24         | 24    |
|  | %     | 0%       | 100%       | 100%  |
| Family Home at T1 and T3                                     | n     | 9        | 8          | 17    |
|  | %     | 52.9%    | 47.1%      | 100%  |
| Moved from Congregated Setting T1 to Personalised Setting T3 | n     | 0        | 5          | 5     |
|  | %     | 0%       | 100%       | 100%  |
| Moved from Congregated Setting T1 to Group home T3           | n     | 0        | 21         | 21    |
|  | %     | 0%       | 100%       | 100%  |
|  | Total | 17       | 72         | 89    |

NB Table reports only data of those who responded to the question 'are you in paid employment?'

#### 4.2.2 Mental Health Problems

From a total of 41 people with MHP who answered the question 'are you in paid employment?' at T3, only one person was in paid employment. This person moved from a congregated to a personalised setting. The remaining samples across all the living arrangements were unemployed (see Table 4.3). Therefore, the data indicates that a high rate of unemployment prevails among people with MHP throughout the different settings where they live.

Table 4.3  
*Employment/unemployment situation for participants with mental health problems by accommodation at T3*

| <b>Type of accommodation</b>                         |                   | <b>Employed</b> | <b>Unemployed</b> | <b>Total</b> |
|--|-------------------|-----------------|-------------------|--------------|
| Personalised Setting at T1 and T3                    | n                 | 0               | 9                 | 9            |
|  | %                 | 0%              | 100%              | 100%         |
| Congregated Setting at T1 and T3                     | n                 | 0               | 11                | 11           |
|  | %                 | 0%              | 100%              | 100%         |
| Family Home at T1 and T3                             | n                 | 0               | 1                 | 1            |
|  | %                 | 0%              | 100%              | 100%         |
| Moved from Congregated Setting T1 to Personalised T3 | n                 | 1               | 12                | 13           |
|  | %                 | 7.7%            | 92.3%             | 100%         |
| Moved from Congregated Setting T1 to Group home T3   | n                 | 0               | 7                 | 7            |
|  | %                 | 0%              | 100%              | 100%         |
|  | <b>Total (n=)</b> | <b>1</b>        | <b>40</b>         | <b>41</b>    |

NB Table reports only data of those who responded to the question 'are you in paid employment?'

The Quantitative data indicates that more people with ID are in employment in comparison to those with MHP. In relation to living arrangement, individuals living in personalised setting and in family homes are more likely to be employed. It is worth taking into consideration that the sample size may have an effect on the findings as the number of people with ID participating in the study is larger than the number of people with MHP (105 and 60 respectively). Similarly, some data is missing as some participants did not respond to the question 'Are you in paid employment?'

### 4.3 Voluntary Work Findings

Some authors consider that voluntary work is a form of employment because it does involve an activity to which one dedicates their time. Therefore, exploring the incidence of people with ID and those with MHP engaged in voluntary work was important in this study so as to provide a wider picture of employment for people with

disabilities. This section answers RQ 1b. What is the voluntary work situation of people with ID and MHP?

Table 4.4 shows that from a total of 103 people with ID only 16 persons were engaged in voluntary work and only 4 out of 59 individuals with MHP were engaged in voluntary work at T1. Likewise, at T3 figures remained similar (14 persons with ID and 6 with MHP were volunteering). When comparing this data with paid employment, people with MHP seem to be more engaged with voluntary work than with paid employment; in fact 2 out of 46 were in paid employment at T3, while 6 of 47 were engaged in voluntary work at T3. However, in sum, the data suggests, again, that the vast majority of participants were not engaged in voluntary work.

Table 4.4  
Volunteering/Non-volunteering by type of disability at T1 and T3

| Type of disability      |   | Time 1       |                  |       | Time 3       |                  |       |
|-------------------------|---|--------------|------------------|-------|--------------|------------------|-------|
|                         |   | Volunteering | Non-volunteering | Total | Volunteering | Non-volunteering | Total |
| Intellectual disability | n | 16           | 87               | 103   | 14           | 89               | 103   |
|                         | % | 15.5%        | 84.5%            | 100%  | 13.6%        | 86.4%            | 100%  |
| Mental health problems  | n | 4            | 55               | 59    | 6            | 41               | 47    |
|                         | % | 6.8%         | 93.2%            | 100%  | 12.8%        | 87.2%            | 100%  |
| Total (n=)              |   | 22           | 142              | 162   | 20           | 130              | 150   |

NB Table reports only data of those who responded to the question 'Do you undertake any voluntary work in the community?'

### 4.3.1 Intellectual Disability

Similarly to paid employment, levels of voluntary work were low among people with ID. Table 4.5 shows the percentages of people with ID engaged in voluntary work in each type of accommodation at T3. Data indicates that from a total of 98 persons with ID, those living in personalised settings were more involved in voluntary work (4 out of 25 persons), followed by those who moved from congregated to group homes (3 out of 28 persons).



Table 4.5

*People with ID engaged in voluntary work by accommodation at T3*

| <u>Type of accommodation</u>                 |            | <u>Volunteering</u> | <u>No-volunteering</u> | <u>Total</u> |
|--|------------|---------------------|------------------------|--------------|
| Personalised at T1 and T3                    | n          | 4                   | 21                     | 25           |
|  | %          | 16%                 | 84%                    | 100%         |
| Congregated at T1 and T3                     | n          | 2                   | 22                     | 24           |
|  | %          | 7.3%                | 91.7%                  | 100%         |
| Family at T1 and T3                          | n          | 1                   | 15                     | 16           |
|  | %          | 6.3%                | 93.8%                  | 100%         |
| Moved from Congregated T1 to Personalised T3 | n          | 0                   | 5                      | 5            |
|  | %          | 0%                  | 100%                   | 100%         |
| Moved from Congregated T1 to Group home T3   | n          | 3                   | 25                     | 28           |
|  | %          | 10.7%               | 89.3%                  | 100%         |
|  | Total (n=) | 10                  | 88                     | 98           |

NB Table reports only data of those who responded to the question 'Do you undertake any voluntary work in the community?'

### 4.3.2 Mental Health Problems

The findings for people with MHP (n=41) who answered to the question 'Do you undertake any voluntary work in the community?' at T3, closely resembled those with ID, with those living in personalised settings at T1 and T3 the most involved in voluntary work (33%), followed by those who moved from congregated to personalised settings with 15%. See table 4.6 for details.

Table 4.6

*People with mental health problems engaged in voluntary work by type of accommodation at T3*

| <b>Type of accommodation</b>                 |            | <b>Volunteering</b> | <b>No-volunteering</b> | <b>Total</b> |
|--|------------|---------------------|------------------------|--------------|
| Personalised at T1 and T3                    | n          | 3                   | 6                      | 9            |
|  | %          | 33.3%               | 67.3%                  | 100%         |
| Congregated at T1 and T3                     | n          | 1                   | 10                     | 11           |
|  | %          | 9.1%                | 90.9%                  | 100%         |
| Family at T1 and T3                          | n          | 0                   | 1                      | 1            |
|  | %          | 0%                  | 100%                   | 100%         |
| Moved from Congregated T1 to Personalised T3 | n          | 2                   | 11                     | 13           |
|  | %          | 15.4%               | 84.6%                  | 100%         |
| Moved from Congregated T1 to Group home T3   | n          | 0                   | 7                      | 7            |
|  | %          | 0%                  | 100%                   | 100%         |
|  | Total (n=) | 6                   | 35                     | 41           |

NB Table reports only data of those who responded to the question 'Do you undertake any voluntary work in the community?'

The Quantitative data indicates that although there is very little participation in voluntary work amongst people with ID and with MHP, those who live in personalised settings are more engaged. Also, similar to the findings on paid employment, those with an ID are more likely to participate in volunteering than those with MHP.

#### **4.4 Community Activity**

This section answers RQ.3 Is there a relation between community activity levels and employment status?

An independent samples t-test was conducted to compare levels of community activity between employed and unemployed individuals with ID and MHP. There was a significant difference in the scores between those employed and unemployed,  $t(74)$

= -2.53,  $p > .05$ , two tailed with employed individuals ( $M = 3.93$ ,  $SD = 1.95$ ) scoring higher than unemployed individuals ( $M = 2.47$ ,  $SD = 1.99$ ). The magnitude of the differences in the means (mean difference = -1.46, 95% CI: -2.66 to -.25) was medium ( $\eta^2 = .07$ ). These results, shown below in tables 4.7 and 4.8, suggest that employment status (employed or unemployed) does have an effect on the levels of community activity. Specifically, these results suggest that when people with disabilities (with ID and with MHP) are employed, they participate in more activities in the community.

Table 4.7

| <i>Descriptive statistics t-test</i> |    |      |      |                 |
|--------------------------------------|----|------|------|-----------------|
|                                      | n= | M    | SD   | Std. Error Mean |
| Unemployed                           | 62 | 2.47 | 1.99 | .25             |
| Employed                             | 14 | 3.93 | 1.95 | .52             |

Table 4. 8

| <i>Independent samples t-test results for unemployed and employed</i> |       |       |                              |                 |                             |       |
|---|-------|-------|------------------------------|-----------------|-----------------------------|-------|
|   | t     | df    | t-test for equality of means |                 |                             |       |
|   |       |       | Sig. (2-tailed)              | Mean Difference | 95 % CI for mean difference |       |
|   |       |       |                              |                 | Lower                       | Upper |
| Equal variances assumed   | -2.49 | 74    | .015                         | -1.46           | -2.63                       | -.29  |
| Equal variances not assumed   | -2.53 | 19.67 | .020                         | -1.46           | -2.66                       | -.25  |

## 4.5 Personalised Settings Case Study

This case study was formed by four persons, two females with ID, a male with ID and a male with MHP. Their pseudonyms are Patricia, Tom, Lucy and Jack. All of them lived in personalised settings at the time of the interview (from November, 2012 to May, 2013). Detailed background information on all four is provided in Appendix IX. There were a total of six informants: three persons with disability and three key workers. (See table 4.9)

Table 4.9

| <i>Personalised setting/Informants</i> |            |                           |                   |
|--|------------|---------------------------|-------------------|
| <u>NAME (Pseudonym)</u>                | <u>AGE</u> | <u>TYPE OF DISABILITY</u> | <u>INFORMANTS</u> |
| Patricia                               | 51         | ID                        | P KW *            |
| Tom                                    | 54         | ID                        | P KW              |
| Lucy                                   | 53         | ID                        | P KW              |
| Jack                                   | 57         | MHP                       | P                 |

Note.\*P: person with ID or MHP; KW: key worker.

### 4.5.1 Categories and Themes

Life for people in employment situations living in personalised settings was characterised by numerous themes and sub-themes that emerged from the analysis of participants' accounts of living in personalised settings. These themes and sub-themes were then categorised into four main headings; 1) Living by one's own rules; 2) Controlling one's own life; 3) Social engagements and networks; and 4) Future Plans and Employment. (See table 4.10)

Table 4.10

*Themes and sub-themes in Personalised settings*

| <u>Categories</u>                 | <u>Themes &amp; sub-themes</u>  |
|-----------------------------------|---|
| 1) Living by one's own rules      | <ul style="list-style-type: none"> <li>• Description of the living accommodation (previous and current)</li> <li>• Transition from one setting to another</li> <li>• Independence</li> <li>• Independent Living Skills</li> </ul> |
| 2) Controlling one's own life     | <ul style="list-style-type: none"> <li>• Self-determination</li> <li>• Choice</li> <li>• Freedom</li> </ul>   |
| 3) Social engagement and networks | <ul style="list-style-type: none"> <li>• Community activities</li> <li>• Contact with people (family, friends, staff and the wider population)</li> <li>• Stigma</li> </ul>   |
| 4) Future Plans and employment    | <ul style="list-style-type: none"> <li>• Paid employment</li> <li>• Voluntary work</li> </ul>   |

**4.5.2 Living by one's own rules**

After moving from congregated to personalised settings, stakeholders described their new environment and compared to their previous setting, in relation to environment, support, and how the move to personalised settings had changed their perspectives of themselves. Living under their own rules was a new experience for each of the participants, it was a journey where the learning process was an important part of unlearning the rules from institutions and learning to create their own ones and increase their independence.

Description of Accommodation:

Some of the participants describe their new surroundings:

*"I love it, I have more freedom here. I can do more things here"* (Tom, November 2012).

*“This place is great... I like the atmosphere of the house. It’s nice and quiet and there is nobody annoying you. It is a good atmosphere and it is lovely here, it is quite safe... I am like in heaven” (Lucy, February 2013).*

Some key workers described residential/congregated settings using the same words ‘rules’ and ‘regulations’; implying that there was a lack of individualisation, whereas in the personalised settings they (participants) did not have to obey rules and regulations, only their own.

*“She (Patricia) would have been under rules and regulations and receipts and the general health and safety practices and policies that go with every institution in Ireland. So they are treated like a group and it is not ideal by any means” (Patricia’s key worker, December 2012)*

*“Tom’s situation now, from two years ago, is totally different [he moved] from being in a residential house set to a timetable [...to] a normal typical life doing things you want when you want and how you want to do them, making your own choices” (Tom’s key worker, November, 2012)*

Transition from one setting to another:

Jack underlined several times the importance of staff, of their attitude and support before, during and after the move from institutions to independent living and Lucy mentioned her experience which backed up Jacks theory;

*“it does require a degree of courage, it does require a great backup support system in the initial stages and you shouldn’t move...unless you truly believe in your heart and soul that you are capable; it should be a gradual process...and before the move the person and the people in the backup team, should be convinced ‘this person is ready’” (Jack, February 2013).*

*“I was in work one day and I came back the next evening and I was shoved out the door. I didn’t get notice about it at all. I wouldn’t mind but I was jaded and tired and I...asked ‘when am I moving out of here, no one has said*

*anything about it', and he (a staff member) said the next day. Sure I wasn't prepared for the next day...I would have liked to get some notice about it...I was not prepared for the next day and for doing everything on my own...I wasn't ready"* (Lucy, February 2013).

#### Independence:

Patricia summarised in three words the things she liked about living in the personalised setting the "*independence*", the "*freedom*" and "*living alone*". Other mentions of the gained independence include:

*"[I like] the security, the independence, the privacy, the location...the serenity... it is in a lovely location and it is peaceful"* (Jack, February 2013).

*"She is very independent. She has only five to ten hours support per week and myself popping in and out"* (Patricia's key worker, December 2012)

#### Independent Living Skills:

Throughout their interviews, the participants spoke about the new skills they had or were learning so as to rely less on others.

*"First, I used to be terrible nervous about [getting] money on my own, now I get used to it, now I can do it myself" and "I can go on the busses on my own [and] I do my own shopping"* (Patricia, December 2012).

*"I can do more things here now [like] I do a lot of walking [and] I like cooking healthy stuff"* (Tom, November 2012).

*"I wake up in the morning and I make my own breakfast and then if I have to go out, I go out and then I do my own washing, I...tidy up the house [and I] make sure that everything is clean and tidy"* (Lucy, February 2013).

Additionally, key workers gave an account of the participants' achievements and indicated the impact that it had on their lives:

*“She just likes so she can go in now on her own front door...she sets the alarm on the house [and] she locks up the house... [She is] learning about cooking... So like buying food, she’s never had to do that before because everything has been [done for her]. So for somebody who has lived in a residential for all that time (40 years) and to actually go out now and start buying it’s huge, you know”* (Lucy’s key worker, February 2013).

*“Tom comes and goes as he pleases, he is more independent; where he lives now Tom actually has a few support workers so he has a choice of his support workers.”* (Tom’s key worker, November 2012).

Furthermore, Tom’s key worker emphasised that support staff play a core role in teaching Tom new skills that are useful and enjoyable and how important the staff’s qualities and skill-sets are to the person supported:

*“... each one (support staff) comes with a skill that Tom has an interest in. So... it enriches his life as they are able to teach him a skill that he wants to learn. There last week Tom learnt to bake a Christmas cake, with one of the guys who is a baker. Tom loves baking and cooking...”* (Tom’s key worker, November 2012).

Moving from congregated to personalised settings involved important changes in the participants’ independence. The findings showed that the participants were happy with their new life in personalised settings and would recommend it to others, provided there is adequate support available to help them transition to their new environment.

#### **4.5.3 Controlling one’s own life**

This category contains the themes relating to self-determination, choice, and freedom, which are essential for the participants if they are to take full control of their own lives.



Self-determination:

Self-determination and confidence were a crucial part of moving to new settings.

Both Tom and Jack reference the importance;

*“They (support staff) are very good in helping you out you know...you build up confidence in yourself. I am happy now the way I am and as are they”* (Tom, November 2012).

*“[The main difference is] my peace of mind, which was very important and most importantly is I have a greater degree of self-worth...because you lose that, you know, you lose a lot of dignity”,* (Jack, February 2013).

Choice:

Related to the right to live independently, it is now recognised the right to choose where and with whom to live is a basic human right; participants mentioned the choices they made from the beginning of the move from congregated to personalised settings.

*“she was involved in decorating the house, that was all of her, we went shopping, she picked the colours [and] she decided what she wanted in the house”* (Lucy’s Key worker, February 2013)

*“...so he has a choice of his support workers. He picks who works with him, when they work with him and picks where he wants to go.”*(Tom’s key worker, November 2012)

Freedom:

The freedom to make one’s own decisions was a recurring theme throughout the interviews. Patricia’s key worker mentioned how she loved the freedom to go wherever she wanted to, while Tom’s key worker mentioned how Tom used his freedom to change one of his support workers.

*“I think she loves the independence of it and the freedom to come and go as she pleases and go where she likes, when she likes. There are absolutely no*

*boundaries from us (staff) around where and how she goes.” (Patricia’s key worker, December 2012).*

*“...he had a support worker that...wasn’t compatible with him and he came to me and asked could he ask this person to move on?” (Tom’s key worker, November 2012).*

However in his narrative, it was identified that while Tom was more confident to make his own decisions, there was still a tone of seeking authorisation from his key worker to take decisions. This seeking authorization was also identified by other key workers, especially after first moving. Perhaps the image of authority that resided with the key worker was associated with resemblance of authority from congregated settings where they previously lived, where they did not make decisions on their own:

*“She would have to seek permission and let people know where she was going and when she was going and if she could go...She would have initially and I keep saying to her that ‘you don’t have to ask me anything, this is your home and your life” (Patricia’s key worker, December, 2012).*

#### **4.5.4 Social engagement and networks**

This category contains the themes relating to Community Activities, Contact with people, and Stigma.

Community Activities:

The findings indicated the importance of integrating with the local communities to help improve the lives of the participants and give them an opportunity to do things they have not previously done before.

*“They (support staff) help me...getting involved in the walking club ...I can do more things [like] walking to work; exercising in the gym...I do Thai Chi on a Tuesday now” (Tom, November 2012)*

*“now that she is living in the community she wants to go to bingo and she wants to drop join the drama group .”* (Lucy’s key worker, February, 2013).

#### Contact with People:

The contact with family, friends/neighbours, and the wider population is crucial in determining what life is like for those who have moved from congregated to personal settings. It was noted that participants did not mention the relationship with their families. Key workers alluded to poor relationships:

*“family connections...for Lucy is huge because she used to go and visit her family and when her parents past away dynamics changed in the family and she doesn’t get to go to back anymore...I think there is kind of difficulties between her and one of her sisters.”* (Lucy’s key worker, February, 2013).

*“I am not in control of things in her family so there is nothing I can do only support her”* (Patricia’s key worker, December 2012).

Tom has developed good relationships with his neighbours. When he was asked what was special about where he lived, this was his reply:

*“The next door neighbours. If there is any bother I can go out to them [...] they watch out for you”* (Tom, November 2012)

Lucy’s key worker also commented on Lucy’s friendship with her neighbours:

*“she likes...meeting the neighbours...she actually met the girls next door herself [when] she was out having a cigarette and they came along and they started talking...she kind of started a friendship with the neighbours”* (Lucy’s key worker, February 2013)

#### 4.5.5 Future Plans

This category contains the themes relating to Employment and Voluntary work.

Employment:

Since all participants had experienced paid employment and/or being engaged in voluntary work, it was expected that they would all share some experiences. However, only some participants and their key workers mentioned employment briefly.

When Tom was asked what other support he would need in the coming months, he answered that it was in relation with employment. He identified having a job as a source of income; his words identified the support that he received from his key worker in giving him ideas on the potential jobs:

*“I would like to get a job now. I think [my key worker] was saying there is a place where they are cleaning out offices and stuff like that. [Before] I worked a couple of hours to get a few pounds you know”* (Tom, November, 2012)

Lucy said that since she moved to her new place, she had not attended work, which reflects absenteeism, perhaps as a mechanism to cope with change: *“I haven’t been at work a lot; I have been ringing them telling them that I am moving and I have lots of things to do. I need a little bit of time and space for myself.”*

The key workers are involved in finding paid employment opportunities; in other words, as staff in personalised settings gets to know the person more, their likes, dislikes, and their abilities, they tend to become active in looking for paid employment opportunities.

*“I have actually looked into a job opportunity for him a job placement, actually, paid employment for him. Hopefully it will come to light in the next week or*

*so...I hope paid employment would make a difference to his life” (Tom’s key worker, November, 2012).*

*“I am just going to look around and see, see what she really likes to do and if there is a chance to get her paid employment So that’s something in the future...the next step would be, I wouldn’t overwhelm her either, but would be [that] she has to get a job” (Lucy’s key worker, February 2013)*

Tom’s key worker noted that since Tom started being engaged in involuntary work he had more contact with the community.

*“He does voluntary work in a local ‘charity shop’ and he has more of a social life” (Tom’s key worker, November 2012).*

#### **4.6 Congregated Settings Case Study**

This case study is formed by three persons, two females with ID and a male with MHP. Their pseudonyms are Janet, Paul and Maureen. At the time of the interview (February to March, 2013), Janet was living in an institution for people with intellectual disabilities. Paul was living in a community hospital for people with mental illness and Maureen was living in a group home. Detailed background information on all three is provided in Appendix X. Each setting has different characteristics as described in previous sections. However, the three varieties within the ‘congregated settings’ case study shared the fact that people allocated in these places had no choice over where and with whom to live. In this case study there was a total of eight informants: two persons with disabilities, three relatives and three key workers. (See table 4.11).

Note: Maureen is the only participant in the study who was not interviewed for reasons out of control of the researcher as this is a secondary data analysis. Here, due to the variety of settings within the classification, the words institution, hospital and group home will be used instead of congregated setting where necessary.

Table 4.11

| <i>Personalised setting- Stakeholders</i> |            |                           |                   |
|---|------------|---------------------------|-------------------|
| <u>NAME (Pseudonym)</u>                   | <u>AGE</u> | <u>TYPE OF DISABILITY</u> | <u>INFORMANTS</u> |
| Janet                                     | 61         | ID                        | P R KW *          |
| Paul                                      | 61         | MHP                       | P R KW            |
| Maureen                                   | 38         | ID                        | R KW              |

Note. \*P: person with disability; R: relative and KW: key worker.

#### 4.6.1 Categories and Themes

A number of themes emerged from the case study for people living in congregated settings. These themes were then categorised into four main headings; 1) Yearning to move from Congregated settings; 2) Relying on someone else's decisions; 3) Deficiencies in the institutional system; and 4) Future Plans. (See table 4.12)

Table 4.12

| <u>Categories</u>                                 | <u>Themes &amp; sub-themes</u>  |
|---|---|
| 1) Yearning to move out from congregated settings | <ul style="list-style-type: none"> <li>• Description of the living accommodation (previous and current)</li> </ul>  |
| 2) Relying in someone else's decisions            | <ul style="list-style-type: none"> <li>• Poor self-determination</li> <li>• Lack of choices</li> <li>• Over-reliance</li> </ul>   |
| 3) Deficiencies on the institutional system       | <ul style="list-style-type: none"> <li>• Preventing independence</li> <li>• Poor social engagement</li> <li>• Lack of training and support</li> <li>• Stigma</li> </ul> |
| 4) Future Plans                                   | <ul style="list-style-type: none"> <li>• Future Expectations</li> <li>• Paid Employment &amp; Voluntary work</li> </ul>   |

#### 4.6.2 Yearning to move from Congregated Settings

Participants living in congregated settings expressed their desire to move to personalised settings. They expressed their concerns and dislikes about institutions where they have lived for years, not by choice but through lack of options and alternative living accommodations with personalised assistance.

Describing the living Accommodation:

When participants were asked what the positive things about living in the congregated settings were, Janet said: *'I am not very happy'*. While Paul expressed that he felt secure in relation to the staff controlling his medication, however, his narrative depicted feelings of sadness and powerlessness:

*"Well I like the security of it. And it's a place where we can experience uh, you know, depression or alienation we can be in danger of being sent to hospital, because, you know, they are keeping a close eye on me. And if I deviate one way or the other, either up or down, they will ring the doc[tor] and get a few extra medications, included in my cocktail. I know that sounds a bit draconian but the point I am making is if I was living by myself I could go for weeks without changing my medication and that could be trouble"* (Paul, January 2013)

Janet expressed repeatedly during the interview her desire to move in to a personalised setting, or as she called it to 'her house':

*"I want to be in my own house...I am not very happy (in the institution). The centre is too old. I want to go into my nice house"* (Janet, March 2013).

Janet's desire to move to 'a house' was confirmed by her relative (father) and her key worker; their narratives underlined her strong dislike for the congregated setting and her desire to move out was expressed as follows:

*“The move is what she has been looking forward to the whole time. She has been going on about nothing else for the past year.”* (Janet’s father, March 2013)

*“She says ‘I am going to this house and I am so happy because I hate it here’. She has said this for the past 12 months that she hates it here”,* (Janet’s key worker, March 2013)

Janet’s father also expressed his thoughts about moving to independent living and considered it an improvement for whoever is taking that step. He said that anyone who wants to leave congregated settings *“should be getting the support [to move]...into the community and into a bit of normality; rather than being institutionalised. I think it is far better for anyone to...have the freedom to move around a place”*. Janet’s father narrative served as a reflection about how restrictive a congregated setting is, hindering freedom, depriving from making choices and limiting opportunities.

Paul’s desire to move to another type of setting is contradictory, as on the one hand he wanted to do it, but on the other, he was not optimistic because he did not self-medicate. Furthermore, he talked about the downsides of living on his own, such as isolation. He expressed those mixed feelings as follows:

*“Moving to my new place? I think at the present time it is not a possibility, because I’m not self-medicating. And I’m not even sure if it would be a good idea because I would be more isolated then, living in my own place. I think that there is something to be said for all of its limitations, for community living. Interacting living, you know, supported living. That’s what I have to say about that”* (Paul, January 2013).

Paul’s relative and his key worker were of the opinion that he wanted to leave the congregated setting. What is more, his relative expressed that the family did not encourage him because, to their consideration, was not the right moment for him to move.



*“Well he definitely wants to leave [the congregated setting]... he said it too twelve months ago but we really didn’t take much notice of it, we didn’t encourage it because we thought, we didn’t think he was ready to go”, (Paul’s relative, January 2013).*

*“...he would like to live on his own and, you know, have his own space” (Paul’s key worker, January 2013).*

In Maureen’s case, she was after moving to a group home, then, there was no report of her wanting to change her accommodation. The only account in this regard was from his father who said *“I think she has improved a lot since she moved here. Maybe it is because the numbers are not as great as they were in [the institution]”*.

Although participants expressed their yearning to move out from the congregated settings, they remained in them. The causes expressed by participants were the lack of other options; it was also reported that a lack of support and particularly because of their reliance on the institutional system as explored below.

#### **4.6.3 Relying on someone else’s decisions**

Lack of Choices:

Paul talked about the fact that he, and other people living there were not there by choice, but precisely for the lack of housing alternatives; resulting on their staying in the hospital for people with mental health problems:

*“the people that live here aren’t here by choice, including myself...It’s not an intentional community, it’s a community of people who would possibly rather be somewhere else but they don’t have the choice because there isn’t anywhere to go” (Paul, January, 2013).*

Poor self-determination:

Participants talked about obstacles in accessing real opportunities to choose where to live and those limitations seemed enforced by expectations and decisions taken by 'others' rather than the person with ID or MHP choices. For instance, when Paul, was asked in what ways was he helped to move out from the congregated setting, he answered that professionals were of the opinion that he was not ready to move. In Paul's narrative there an over-riding feeling of hopelessness and concern about managing his medication, assuming a passive role while relying in professionals administering his medication twice a day.

*"They haven't done anything to help me move to a new place, because the conventional wisdom as I understand it is I'm not ready to move in to a new place, because I'm not self-medicated, they give me my medication in the morning and evening"* (Paul, January 2013).

Over-reliance on the Institutions

Not only the participants, but their relatives were reliant on the services and their staff, accepting their authority to make decisions for the person supported, and also on their behalf:

*"Well I didn't go through that process (move to the group home). It was the people in the 'service for disabled' that organised it. We had not input into this at all really. They just kept us up to date with what was going on and what the overall plan was for Maureen to move her out to a house. We left it to them and it slowly progressed. Next they were moving her."* (Maureen's father, January 2013)

Similarly, the fact that families who have their relative in a congregated setting were not directly responsible for covering the needs or dealing with the person supported on a daily basis, gave them a feeling of relief. This was expressed by them as follows:

*“Well in fairness, we are happy with [the community hospital], without them we are not sure how we would cope with him”* (Paul’s relative, January 2013).

*“When me and her mother are dead and gone we know she is going to be looked after and it is the only peace of mind we got”* (Maureen’s father, January 2013).

Janet’s father said that he did not know anything about the services his daughter was getting to move out of the institution besides *“getting her used to moving and being outside the place (the institution)”*. Additionally, when he was asked about how he could get involve on it, he answered: *“I don’t know of any way I could be better involved with it to be honest. No”*. All his answers represented a complete lack of knowledge about Janet’s needs and her likes. But they also showed his unwillingness to get involved in the process to support her in the move out form the congregated setting.

Likewise, when Maureen’s father was asked about the support that her daughter might need in the near future, he answered: *‘I don’t really know and I wouldn’t be qualified enough to express an opinion on that’*. His answer indicated, again, his reliance on the services while showing disengagement with Maureen’s needs and the absence of planning in relation to personalised support.

#### **4.6.4 Deficiencies in the Institutional System**

Preventing Independence:

Consistent with the often criticised practices in congregated settings, Janet’s key worker highlighted wrong practices in the institution where Janet was living. There, she was given no opportunities to carry out basic personal care tasks that she was able to do, thereby hindering Janet’s self-sufficiency. The following quote suggested that the reasons for these incorrect practices were the lack of flexibility in that environment, where everything must be done by a certain time in a certain way, with no room for denunciation:

*“...I shouldn’t be saying that but it’s kind of political...it is totally ridiculous to hurry up things in the mornings and kind of dress her. She is well able to do it herself...and I think that’s totally ridiculous cause she is fairly independent and...all those things have been taken from her independence; and...it is a difficult area to say these things to other staff. I sort of feel she is very capable and should be doing it”* (Janet’s key worker, March 2013).

Janet talked about the things that she can do, but as observed above, this was not taken into consideration by staff in the congregated setting.

*“I do the washing up and drying up and setting the table...and I am able to shower myself, (Janet, March 2013)*

The above example represented the lack of choices and the restriction of autonomy in the institutional system, where carried out are practices that violate the basic rights of disabled people.

#### Lack of Training and Support:

There was no direct account of the participants in relation to the support provided in the congregated settings however, their relatives and key workers mentioned situations that were important to consider, in order to understand the realities of people with ID and MHP living in congregated settings. For instance, Paul’s key worker expressed her reflections about her lacking of training on creating awareness:

*“I [am] trying to create awareness that...medication. [But ...] being honest we haven’t made very much progress...the only concern [is that] I don’t know how to create awareness really and to help him accept that he has mental illness.”*

Once again, practices in the congregated setting were reported by Janet’s key worker, indicating the disinterest from staff to attend individual needs.

*“Sometimes she (Janet) feels that staff are not listening to her. She kind of feels she wants to leave here, she hates it here and wants to go to this house (independent living)”,* (Janet’s key worker, March 2013).

### Poor Social Engagement:

The following accounts suggested that in congregated settings there was a perceived need for a more stimulating environment and more activities that could allow people to have better contact with the community.

*“Well it’s boring at night...I’d like some kind of organized night activity, games, stuff like that. I would also like more outings” (Paul, January 2013)*

According to the key worker, in the group home activities in the community in the evening time were jeopardized by the lack of staff. Furthermore, it was evident that each group home did not operate autonomously with an independent set of staff, but it was rather determined by daily needs and circumstances. Therefore, Maureen and people living in that group home lacked activities and choices due to the ever-changing staff supporting them.

*“I think if we (staff) had more support staff to get her out more [it would be different because] with sickness in the house it is sort of restricted, restricted movement...if we had more staff in the evenings, more clients would go out in the evenings. Even if there is one sick in the house there is someone there to mind them...At the moment if we have a gap we are drawing from other houses (group homes) that can’t afford to give us that staff” (Maureen’s key worker)*

### Stigma:

Another key feature highlighted in Paul’s narrative was elements of stigma such as labelling, stereotyping, separation and status loss as a result of the power of institutional care over him. These elements arose from how living in congregated settings was interiorised by the participant and by how his relative referred to him. For example, stigma is identifiable in how Paul referred to himself as part of a group, which represents status loss and separation from the wider population to be reduced to a member of an institution. Paul said: *“in the [hospital] there are approximately 16*

*people living there; known as the residents*". Paul expressed further on in the interview that staff *"liaise with the residents on a cheerful basis...[They] offer us support and by us I mean the residents"*.

Moreover, at various points in the interview, Paul's brother mentioned Paul's rejection to being 'institutionalised' *"he sometimes would not eat the food in the institution for no particular reason other than it is institutional food"*. Later on he said: *"he (Paul) doesn't like to hang out (with other residents)"*. His key worker also mentioned: *"he doesn't like to be involved in group things that the service would provide because he doesn't like to be with other patients...he doesn't like the association because he really hasn't accept his illness [When he is associated] with other people with mental illness...he [is] embarrassed about it'*. Those narratives about Paul's behaviour gave account of his rejection to labels and stereotypes to which, against his desire, he is subjected to.

In addition, there was stigma also in the way Paul's brother and the staff talked about him. Condemning him to low achievements based on his mental health:

*"He has a good brain...you wouldn't think the guy was uh mm you know? He has the ability alright but the illness will always prevent him seeing out his potential...as the nurses would say 'he is intelligent to a certain degree'."*  
(Paul's relative, January 2013).

Similarly, Maureen's father referred to his daughter on a stigmatising way: *"You are never going to achieve what you like with Maureen, you have to be realistic, she is what she is but any little achievement would be marvellous"*.

How stakeholders expressed about the person supported is closely related to the low expectations also mentioned by their key workers and relatives.

#### 4.6.5 Future Plans

Expectations for the future:

When asked about the expected benefits from personalised settings in comparison to congregated settings, Janet's key worker said:

*"I think she will do very well, she will gain more confidence...she will do very well in a small setting"* (Janet's key worker, March 2013).

Two participants in this case study were over 60 years of age. The expectation for their future, from the point of view of their relatives was not going to be a radical change, but they expected for them to have a better life in an environment that was more suitable for them and where the person with disability could feel more content.

*"Unfortunately he is going to be 62 in March and I can't see his life changing too drastically. He is not going to get a job obviously but it is a case of him having a more relaxed life"* (Paul's relative, January 2013).

*"Apparently the future is okay for Janet. It is as good as it is going to be. It is not going to be like winning the lotto or anything like that"* (Janet's father, March 2013).

Maureen was the youngest participant living in congregated setting (38 years of age). However, her father did not have greater expectation than the other relatives, stating that her achievements were going to be limited:

*"Well I think [in the future] she will be able to do more things for herself and be more independent from the training and the help she is getting here. It will be slowly but still...I think she has a fairly good quality of life at the moment and that is all she is ever going to achieve. You just can't hope for miracles."*

The relatives of the participants did not seem to have any great expectations for them mainly due to capability, age, and stereotypes.

#### Employment and Voluntary work:

Participants were engaged in employment or voluntary work; however, there was minimal reference to this during the interviews. Janet, who was planning to start a new job, she said:

*“I got a new job. I am supposed to be starting tomorrow...Hanging up the hangers, not here, in the job in the afternoon 12 or 12:30pm. Somebody will give me a lift down to it”.*

Paul spoke about wanting to get a third level degree which, while not directly stated, could indicate that he wanted it to improve his chances of mainstream employment.

*“I want to do a diploma in social studies in ‘X University’ and other things like that”, (Paul, January 2013).*



## 4.7 Family Home Case Study

The sample for this case study includes two persons with intellectual disability who have lived at their parents' home since birth and at the time of the interviews (February, 2013) were part of a programme to acquire independent living skills. Their pseudonyms are Lisa and Robert, both were interviewed and their perspectives and experiences living in the Family home are described in this section. Detailed background information on both is provided in Appendix XI. Their key workers and mothers provided further information about their lives and the achievements accomplished since the programme started. There were a total of six stakeholders: two persons with disability, two relatives and two key workers. (See table 4.13).

It is worth noting that neither Lisa nor Rob were informed by their parents or key workers about any short-term plan for 'moving' from their family home to another type of accommodation. This was expressed that as follows:

*"...about moving ...we haven't approached that with him yet",* (Robert's mother, February 2013).

*"[Moving from family home to independent living has not been] mentioned to Lisa at the moment, she doesn't want to move out, she is content and happy in her home",* (Lisa's key worker, February 2013).

Table 4.13

| <i>Family home -stakeholders</i> |     |                    |            |
|----------------------------------|-----|--------------------|------------|
| NAME (Pseudonym)                 | AGE | TYPE OF DISABILITY | INFORMANTS |
| Lisa                             | 20  | ID                 | P R KW *   |
| Robert                           | 24  | ID                 | P R KW     |

\*P: person with ID or MHP; R: relative and KW: key worker.

### 4.7.1 Categories and Themes

A number of themes emerged from the case study for people living in congregated settings. These themes were then categorised into three main headings; 1) Aiming for independence; 2) Social Engagement; and 3) Future Plans. (See table 4.14)

Table 4.14

*Themes and sub-themes in Family home*

| <u>Categories</u>                        | <u>Themes &amp; sub-themes</u>  |
|--|---|
| 1) Aiming for independence               | <ul style="list-style-type: none"> <li>• Describing the environment</li> <li>• Learning independent Living Skills</li> <li>• Preventing independence</li> </ul> |
| 2) Social engagement and social networks | <ul style="list-style-type: none"> <li>• Interaction (family, friends, staff and the wider population)</li> </ul>   |
| 3) Future Plans                          | <ul style="list-style-type: none"> <li>• Living Arrangements</li> <li>• Employment</li> <li>• Self-Determination</li> <li>• Parental Ageing</li> </ul>          |

#### 4.7.2 Aiming for Independence

Describing the Environment:

When interviewers asked Lisa and Robert about their plans to move from their family's home, they answered with uncertainty, and expressed that they liked living in their family home:

*"I am not moving to a new house...this is a place that I have to myself in the house...I have my own TV and my bedroom is at the other side...my bedroom used to be my mom's office, but she does not use the office any more" (Lisa, February 2013).*

*I don't know, I think I will [but] I don't know...I'd like to move now...I will see what the plan is. I would like to see [what is the plan, but] I like to live here with mammy and daddy. I am not sure [about moving out] I don't attempt to happen...I didn't hear anything about it (moving to independent living) yet" (Robert, February 2013).*

Robert was doubtful and constantly answered questions by saying "I don't know" or "I am not sure", but he also talked about the things that he enjoyed doing inside and outside the family home: "I like stay [at home] and watch tele[vision the] whole

*time, ...watch soaps...I [also] like going around in the town...walk around the shops".* Lisa also mentioned that what she liked to do in her family home was to have her own television, she said: *"I like the TV you know...I can just watch it by myself because I have it on my own".*

In both families, the parents expressed that they did not want to limit the opportunities for their children in achieving independence and expressed the reasons of their interest in the project of moving to independent living and the programme for acquiring independent living skills.

*"I wouldn't like that just because she has an intellectual disability, that she would never be able to live anywhere else [than the family home], and so my interest in the project really was to start working on getting Lisa more independent at home",* (Lisa's mother, February, 2013).

Similarly, but to a certain point doubtful and apprehensive, Robert's mother supported him in being part of the project to acquire independent living skills.

*"I feel that I was a bit hesitant in the beginning not letting him going into the programme, but now I can see the benefits from it and I don't want to stand in his way",* (Rob's mother, February, 2013).

Both mothers expressed their aspiration for their children to, at some stage in their lives, being prepared to depend less on people and to develop independent living skills.

Learning Independent living skills:

When participants were asked about the new things that they have learned, Lisa expressed that she could do almost everything on her own. In Lisa's words: *"Well, I am 20 years old; I do [everything] mostly myself".* And Robert pointed out the things that he does by himself: *"I put my clothes into the washing machine...all the time now I put, I wash, I put me (sic) cloths on my own and then put washing powder into it and turn on the thing (the washing machine)."* Likewise, their key workers and mothers recognized the variety of skills developed and achieved by Lisa and Robert;

mostly in the areas of preparing their own meals, housekeeping, shopping and using public transport:

*“Well, he can actually...put on the microwave and put Wheatabix for his breakfast and pour the milk, but as far as using the cooker and hob no, Rob wouldn’t know [how to use it]. He needs help around cooking a [full] meal.”* (Robert’s mother, February 2013)

*“She can make things for herself now, you know, she wouldn’t starve. I mean it would not be a full meal but she can cook spaghetti...and she’d do a little bit of housework now.”* (Lisa’s mother, February 2013).

Acquiring independent living skills is a process, therefore besides recognizing their achievements, the areas in which they required further support were also mentioned not only by the person supported but by their mothers and key workers. Lisa’s mother expressed her concerns about Lisa’s disengagement with issues related to her own security such as keeping doors locked:

*“She wouldn’t really be terribly aware of keeping herself safe and secure in a house if she was by herself [in a house, she wouldn’t be aware of things] like making sure that the locks are locked [...], so are lots of areas that could be improved”* (Lisa’s mother, February 2013).

Similarly, Robert’s mother identified the need for support in the area of money management because he would not wait for his change to be given when shopping, despite her constant reminder to wait for his change:

*“He knows a 50 is a 50 and a 20 [is a 20] (notes), but if he went into the shop and he was buying something he would be handing the 20 but he would actually start to walk away from the counter because...he just doesn’t understand money; [even when] I always say Rob ‘you stand, you wait for your receipt and your change’”,* (Robert’s mother, February 2013).

## Preventing Independence:

Regardless of the emphasis above on supporting and recognising Lisa's and Robert's achievements; their mothers, with the purpose of providing care, protection and a safe environment, they unintentionally limited their social, psychological or physical development. When parents were asked in what ways living in the family home was good for the person supported they answered with expressions such as *"everything is laid out for him"* or *"everything is done for her"*. These two expressions comprise the idea of limiting and preventing the independence of the person with disability.

When the mothers were asked about the drawbacks of living in the family home, Lisa's mother identified the ambivalence in doing *"everything for her"*, from her perspective it was good but at the same time was negative. Likewise, she recognised the struggle that she had, as a mother, in changing her own habits of doing everything for Lisa:

*"She gets everything done for her. She is implying to be, you know, just like to get things done for her, like to get quite relaxed about everything, not really want[ing] to do things for herself and there is a temptation you know, you kind of look after her. I would have looked after her ... since she was very small; so it is very hard to get out of the habit and to try to help her to do things for herself."* (Lisa's mother, February 2013)

The problems with changing habits and letting the person with ID be more independent took various forms, the one expressed above where Lisa's mother felt *'tempted'* to keep doing everything for her and it was also present in Robert's mother account, when she kept referring to Robert as a teenager (when he was 24 years of age). Both reflected the difficulties that these mothers had in recognising that their child with disability had become or were in the transition to become adults.

*"...probably like all teenagers, he is just laid back and takes on everything ...mummy is here and mummy does everything for him, you know"*, (Robert's mother, February 2012)

What is more, when the interviewer pointed out that Robert was older than a teenager, the mother would defend her reference by saying “*Oh God, [but] Rob would be back down*”; which gives an account of the mother’s difficulties in accepting that Robert had reached adulthood. Contrarily, his key worker acknowledged Robert’s age and the potential needs that he might have such as engaging with people his own age and moving from what he called the ‘constraining environment’:

*“Rob is [a] 24-25 year old young man, needs to be moving on to this new place, with his own friends. I suppose like any other that age gets frustrated as well with the constraints sometimes at home”.*

Furthermore, Robert’s key worker explained that Rob was in the habit of getting things done for him, which made him hesitant about moving to independent living:

*“I think he likes getting his dinner handed up by his mummy and having the freedom of the house but other times he gets frustrated because he is living at [his family] home”.*

It is worth emphasising that neither Lisa nor Robert complained about living in the family home. When they were asked what they didn’t like about living in their family home, they responded that they liked where they were living. As mentioned before they or their families did not have a plan to move out short-term. However, their engagement in the project was mainly with the finality of acquiring independent living skills for when they move out at some point in the future.

### **4.7.3 Social Engagement**

Social engagement includes social contact (with their families, with friends and people in the community) and mainstream activities in which participants are engaged. Parents and key workers were concerned about the limited contact with people outside the family home. This is what Lisa’s mother said:

*“Obviously she is happy at home and she is happy to live with her family. In some ways I think it keeps her quite isolated...she used to have friends on the road and she referred to people as being her friends. Then, of course, as*

*those girls got older they stop calling. But I mean, she doesn't seem to mind not having friends but it would be more me thinking, you know, she is quite isolated here in the house, and she just has her family basically",* (Lisa's mother, February 2013).

In the previous narrative, there are some issues that are relevant to highlight, for instance, the perception of isolation did not come from Lisa, but from her mother. That was her perception, while as she reported herself; Lisa did not look affected by not having friends.

Lisa and Robert were engaged in employment; Robert worked in a mini supermarket, while Lisa worked one hour a week in a local shop. Those were jobs in the community which facilitates their interaction with people in the community.

Lisa, besides working in the local shop, attended services for disabled people locally. In this regard her mother expressed that Lisa did not know what is expected of her from society because she was in more contact with people with ID than in mainstream services. So she attributed that to her lack of awareness about social norms:

*"[Lisa] has difficulty with knowing what might be expected from her from a social point of view because she doesn't have any example to follow where she is (in the services for disabled that she attends) , so if she was in mainstream more, I think maybe she'll learn a little bit more, I mean it's small little things like, you know, she tends to hum away to herself when she is by herself and sing little songs, and ...other people with intellectual disabilities would sometimes say 'stop singing you are annoying me' and she doesn't understand why she cannot be singing, you know. So, you know all this kind of rules of society I suppose that she is not really aware of."* (Lisa's mother, February 2013).

In another part of the interview, Lisa's mother said that employment in mainstream would be the best way to help her in acquiring social skills and to get to know more people.

#### 4.7.4 Future Plans

Stakeholders considered that the future, specifically, the opportunities for Lisa and Rob envisaging independence, employment and social inclusion would be determined by the support that they received from services and pertinent authorities. Lisa's key worker noted that assisting disabled people in personalised settings changed her perception about them and she could now recognise their potential:

*"...each person has the potential to become who they want to be, not just seat in workshops...each person once they have the support on the ground and go their pace and their level, that they can achieve their dreams"* (Lisa's key worker, February 2013).

Living Arrangements:

Both Robert and Lisa's relatives expressed that they would like a gradual transition to independent living, perhaps facilitated by services available for disabled people. Robert's mother sought respite services for Robert and Lisa's mother talked about the possibility for Lisa to go on holidays for her to 'get used to' be apart from her parents. From Robert's mother point of view, Rob's future was not promising but rather marked by his limitations and she stated:

*"...because of not being able to read or write or manage money, he (Robert) is going to be held back that bit anyway, you know".*

On the contrary, his key worker expressed his yearning for Robert to succeed in achieving independence, and an independent living setting at some stage in the future:

*"I'd love for him to have his own place or be at sharing with other people, I think if we can work on Rob's independence in certain areas it will make it easier to look for paid support because is going to be very specific time".*



These opposed expectations for the future might be delimited by the relation that they have with Robert. First, his mother liked to do everything for him, restricting his independence, whereas his key worker was engaged in encouraging Robert's independence, focusing on his abilities rather than his disability.

Employment:

Although both Robert and Lisa were in employment, their mothers reported that they would like to see them being employed in a job linked to their interests:

*“Lisa, she likes children and my idea at the moment is to organise for her to get some work experience to start with, in a preschool or crèche or something like that and...to get her ready for that and develop the skills that she would need. So, it is something that we are thinking on organising now ourselves where I work”*

*“...if he could get [him] another little job, a few more hours in the morning somewhere farming or something, because he absolutely adores farming... So, [his father] is looking into that at the moment.”* (Robert's mother, February 2013).

Those narratives suggested that the parents play a fundamental role in looking for and finding employment opportunities for their children. Perhaps Lisa and Robert would be amongst the unemployed if they would not have the support from their parents in this regard. This was acknowledged by Lisa's mother and she wondered why was not available a career advocacy service available to disabled people:

*“...it is only an hour that she does in the local shop (working) but I had to organise that for her...as far as I am aware anybody who is attending those day services (for disabled people) [and] who is working elsewhere, as well has been organised by family or the people themselves so I would like to see it as part of the person-centred approach that would, you know, push more towards ‘what else what can this person do?’ Not ‘how can we manage this person [or how can we] keep them amused for the day’”* (Lisa's mother, February 2013)

## Self Determination:

According to Lisa's and Robert's relatives, as a result of receiving training for independent living skills they were becoming more confident in themselves and happier. Lisa's mother mentioned it at different moments throughout the interview as follows:

*"She is happier to try new things than she used to be. She is more confident in being able to do things";*

*"I think it has made a difference to how she thinks about herself and I think that's important";*

*"Before ... she would have said 'would you drive me over to the shops?' or 'can we go to the shops?' Now, if she wants to go to the shop she just gets up and goes by herself"*

Robert's mother mentioned that his self-determination was "...coming on in leaps and bounds" as a result of learning independent living skills and that this would be very important for Robert in the future.

## Parental Ageing:

Lisa and Robert did not provide their expectations for their future as they only answered '*I am not sure*' or '*I don't know*' when interviewers asked about the things that they would like to do in their future. While the following are not their perspectives, it was considered important for the researcher to explore the standpoints of each stakeholder. For instance, Lisa's mother narrative revealed her fears related to the ageing process and her daughter's future when she and her husband will no longer be there to provide Lisa with housing and support:

*"I suppose it will come a time when her dad and myself will be older and she could be my age and still living at home so ...what happens when we (parents) are gone then, you know does she stay living alone which she's never done"*

*on her life before, would she be prepared for that? Probably not” (Lisa’s mother, February 2013)*

Robert’s key worker emphasized the importance of having a living arrangement alternative to family home because it exits the latent possibility of the sudden death of parents and the person with disabilities will be better prepared for moving to independent living if they plan ahead:

*“...even though I think the best thing for Rob is not to be in a traditional set up (an institution)...if something happen to Rob’s parents in the morning I don’t have a plan B and they don’t have a plan A but, you know, in worst case scenario... Rob would end up in a traditional set up because there’s not plan B for Rob at the moment”, (Robert’s key worker, February 2013)*

#### **4.8 Cross Case Analysis**

This section is a cross case analysis of three case studies analysed earlier. The case studies explored the experiences of nine participants, seven persons with ID and two with MHP, living in three different type of settings: personalised settings, congregated settings and the family home. This cross-case analysis seeks to explore further categories that resonate across cases. Those categories will be developed aiming to gain a better understanding of the similar and different life experiences across settings.

The following recurrent themes to be explored arose from the experiences and accounts of participants with ID and MHP, their relatives and their key workers:

- Environmental differences across settings
- Independence and independent living skills
- Decision making and empowerment
- Community activities and relationships with people
- Employment
- Expectations for the future
- Different supports leading to different results

### 4.8.1 Environmental differences across settings

All participants described the place where they were living and there were differences to emphasise (see Table 4.15). First, participants living in personalised settings used positive adjectives such as 'quiet', 'peaceful', 'private' and 'great'. Furthermore, participants explained that it was a place where they felt happier, independent and had gained confidence.

| Summary of environmental differences across settings               |  |  |   |
|--|--|--|---|
|  | Personalised setting   | Congregated setting  | Family Home   |
| Environmental differences across settings reported by stakeholders | <ul style="list-style-type: none"> <li>• Personal space</li> <li>• Choice of home decoration</li> <li>• Have a key to open the door</li> <li>• Peaceful place with freedom and independence</li> </ul> | <ul style="list-style-type: none"> <li>• Security feeling</li> <li>• Desire to move out from congregated setting</li> <li>• Shared facilities and bedroom</li> <li>• Absence of personal space</li> <li>• Control</li> <li>• Guided by 'rules'.</li> </ul> | <ul style="list-style-type: none"> <li>• Security</li> <li>• Having their own belongings</li> <li>• Parents doing 'everything' for them</li> <li>• Parents have the key to the house</li> </ul> |

Contrarily, people living in congregated settings, referred to them as 'old', 'boring' and one participant said it was 'secure' but dangerous at the same time. One of the main features that characterised this setting was the continuous displayed desire to move out from the congregated setting; particularly from one participant with ID, this was verified by her key worker and her relative. In the case of the participant with MHP, he also expressed his wishes to move to an accommodation in the community, but he stated that living on his own might have its limitations such as isolation.

Congregated settings were also described by stakeholders as a place where staff incurred in wrong practices hindering independence and the right to make choices. Some key workers mentioned that those practices were the result of strict rules and staff shortages. For instance, a participant (Janet) who was able to wash and dress herself, was prevented from doing so as staff had a restrictive schedule, rather than allowing the person to do it on her own pace. Those experiences were contrasting to the ones of those living in a personalised setting or in their family home.

In relation to those living in the family home, first of all, it is important to emphasise that participants were in their early 20's, so they were just entering adulthood. They expressed feeling content and happy living with their parents as they had their own belongings and their own rooms. Furthermore, their key workers stated that the person supported seemed happy, but highlighted age related issues such as the need to have their own space and live with people their age, one key worker (Lisa's) criticized that the parents did not give enough responsibilities to their daughter, while another key worker (Robert's) emphasised that despite the fact the person liked living in the family home, it was frustrated at times for the restraints that the accommodation entailed for a young man.

Overall, there were clear differences across the type of accommodation; the only similarity was the feeling of security reported by those living in the congregated setting and the family home. This was probably linked to the feelings of "everything was done" for them by someone else, such as administering medication or providing meals. However, the development of independent living skills was closely related to the type of environment, as analysed in the following section.

#### **4.8.2 Independence and independent living skills (ILS)**

This section will break down the issues related to independence and ILS across the settings. All participants were part of an ILS programme. Therefore, all of them had experiences in this area. However, there were some differences as analysed below (see Table 4.16).

Table 4.16

Summary of independence and ILS across settings

|                      | Personalised Setting   | Congregated setting  | Family Home   |
|----------------------|--|--|---|
| Independence and ILS | <ul style="list-style-type: none"> <li>• Acquiring ILS and using them in their daily life</li> <li>• Personal care, housekeeping and money management (accessing their own money)</li> </ul> | <ul style="list-style-type: none"> <li>• Acquiring ILS, but limited opportunities to apply them to their daily life</li> <li>• Medication is regulated by staff</li> </ul> | <ul style="list-style-type: none"> <li>• Parents ‘allowing’ participants with ID to be in the ILS programme</li> <li>• Acquiring ILS (personal care, housekeeping, money management, using public transport) and using them in their daily life with certain limitations</li> </ul> |

Participants living in personalised settings acquired ILS as part of the programme and they used those skills as part of their daily routine; what is more, one of the participants expressed how since she started, her day, from showering, preparing breakfast, doing the shopping, all those activities were done by herself on her own, when it suited her. While that daily routine is commonly taken for granted for the rest of the population, it was a first step for these participants to live an independent life. Additionally to these experiences, some participants and their key workers talked about using public transport and choosing where to go as a new experience for them. This situation was also shared by those living in the family home. For instance Lisa, a participant with ID learned how to use buses to go to work as part of her programme to acquire ILS. Contrarily, those living in congregated settings, even when they had ILS, the wrong practices across congregated settings limited their

choices and opportunities to develop independence. For example, a participant who was able to get dressed was rushed by staff, not allowing her to do it or to choose what to wear. Those characteristics of congregated settings have been often criticised and participants of this study were also affected by them, creating dependency, such as the case of the participant with MHP, who depended on staff to prompt his medication.

A common goal identified by stakeholders, regardless of their living accommodation was gaining independence and doing this by acquiring ILS. In some cases, the person supported did not mention it, but their key worker or their relative did; which gave an account of the importance of implementing and making accessible ILS programmes to people with disabilities. Nonetheless, all participants reported positive feelings as a result of learning ILS such as confidence, dignity, happiness and 'self-love' as stated by one participant (Jack).

#### **4.8.3 Decision making and empowerment**

Table 4.17 summarised the findings on decision making and empowerment across settings.

This study found that in relation to empowerment, participants living in personalised settings were learning to be in control of their lives; as pointed out by their key workers, it was a process for them as they had experienced institutional practices where decision were taking by staff without consulting them. Furthermore, the majority of key workers supporting people living in personalised settings acknowledged the participants' tendency to seek their permission to do certain things such as spending money or to buy certain items. Those behaviours suggested that the legacy of the institutional system, where authorization was the first step to action. Moreover, key workers reported how they had to constantly remind them: 'this is your home', 'it is your choice', and 'it is your money' to reinforce their empowerment. In general, key workers supporting people in personalised settings seemed to have a good level of empathy, which allowed them to relinquish their control in order to support the person with disability to make her/his own choices and gain confidence.

Table 4.17

Summary of decision making and empowerment across settings

|                                 | Personalised Setting   | Congregated setting  | Family Home   |
|---------------------------------|--|--|---|
| Decision making and empowerment | <ul style="list-style-type: none"> <li>• Learning to make decisions on their own (First steps to empowerment)</li> <li>• Gaining confidence</li> <li>• Seeking permission from key workers (as a legacy of institutional care)</li> <li>• Staff relinquished their control in order to support people with disabilities to make choices and gain confidence (e.g.</li> </ul> | <ul style="list-style-type: none"> <li>• Feeling of powerlessness</li> <li>• Loss of confidence</li> <li>• Their allocation in the setting is not by choice.</li> <li>• Relying on staff decisions (person supported and also their relatives)</li> <li>• Relatives considered that staff were better qualified to know what the person with disability needs</li> <li>• No input on support provided</li> </ul> | <ul style="list-style-type: none"> <li>• Learning to take decisions on their own, however, parents influence those decisions</li> <li>• Gained confidence as a result of learning ILS</li> <li>• Age issues related- entering adulthood.</li> </ul> |

Participants living in congregated settings, expressed feelings of powerlessness and low confidence. One participant highlighted the fact that he and the rest of the people living in the congregated setting were not there by choice, but because of the lack of options. Similarly, the support provided was not individual but communal. The same participant clearly relied on staff in prompting his medication despite him being



aware of the importance of taking his medication; he was unable to identify the gains if he would self-medicate. Similarly, relatives relied on staff and the institutional care, expressing that was a relief that they were cared for, otherwise 'they (family) would not know how to manage'. That statement gave account of the reliance on the institutional system. Likewise, they stated that professionals/staff would be 'better qualified' to decide what assistance they required. Diminishing their involvement in empowering their relative, they supported the institutional system to take decision on their behalf (person supported and relatives).

In relation to participants living in the family home, this study found that empowerment was far from achieved as parents tended to continue to make most decisions on behalf of their child. However, after their experiences with ILS, participants with ID had gained confidence and empowerment as part of their daily life, deciding what to do and where to go. This was an appreciated achievement to their parents as some changes were evident in their children's' behaviours. For instance, one participant refused to go on holidays with his parents and stated clearly his reasons. That act took to his family by surprise; however, they understood and supported his choice of not going with them. Thus, although empowerment was unexpected for parents, it was valued by them, especially because they were reaching adulthood, and this seemed to be understood by one participant's mother, while the other rejected it. Overall, in the family home the family dynamic and their understanding of disability and age-related issues took a core role in the empowerment of the person with disability. Although parents reported apprehension in 'letting' their children to do things on their own, as a result of the ILS programme and from witnessing their achievements, they identified and recognized their children abilities to handle new experiences.

Overall, it was emphasised the importance of learning new ILS especially for the marked difference that it made to participants in their self-esteem and confidence.

### *Community activities and relationships with people*

This study found more differences than similarities across settings in relation to community activities and contact with people (see table 4.18). For instance,

participants living in personalised settings were engaged in the community, they established friendships with the neighbours and key workers. However, they had minimal contact with their relatives, as they key workers underlined. Stigma was mention as a barrier to social inclusion, one participant mentioned how self-stigma had affected his life as he was labelled as a 'psychiatric patient'; similarly, another participant wanted to move to another town in order to not be seen as 'a client' of services for disabled.

| Table 4.18  |   |   |  |
|---|---|---|--|
| Summary of community activities and contact with people across settings |   |   |  |
|   | Personalised Setting  | Congregated setting   | Family Home  |
| Community activities and relationship with people                       | <ul style="list-style-type: none"> <li>• Engagement in community activities of their choice</li> <li>• Relationship with neighbours</li> <li>• Development of a strong relationship with key workers</li> <li>• Minimal contact with their families</li> <li>• Stigma and self-stigma limiting social engagement</li> </ul> | <ul style="list-style-type: none"> <li>• Lack of activities in the community, mainly in the evening time (group home and hospital for people with MHP)</li> <li>• Regular contact with relatives. (Specially the person living in group home)</li> <li>• Activities as a group</li> </ul> | <ul style="list-style-type: none"> <li>• Television main entertainment in the family home</li> <li>• Community activities (going to the cinema and swimming)</li> <li>• Engagement with community facilitated by parents.</li> <li>• Employment as a facilitator of social inclusion and contact with people</li> <li>• Parents concern for minimal friendships</li> </ul> |

For those living in congregated setting, this study found that they have constant contact with their families. The relative of the participant living in the group home highlighted that it was much easier for the family to visit the person in the group home than when she was living in the institution. However, there were no activities in the evening time, both in group home and hospital for MHP.

In the family home, television was a main entertainment, but also had more options as they had a community life style. However, friendship was not mentioned, what is more a participant's mother expressed her concern in this area, trying to find alternatives. Employment was identified as an element that facilitated socialising.

#### **4.8.4 Employment**

All participants, regardless their living accommodation, were either in paid employment or engaged in voluntary work (see Table 4.19). Thus, it was expected to find some key information to gain a better understanding of employed people's lives across the settings. Contrarily to the researcher's expectations, there were only some accounts in this regard. However, there were some findings meritorious of mention and further exploration. First, employment was identified by key workers in personalised settings and by parents in the family home as a means to socialise and get involved in the community. Stakeholders emphasised the importance of mainstream employment, where the person could learn the 'rules of society', rather than in workshops for people with disabilities. In this regards, there were no comments from relatives or key workers of participants living in congregated settings.

Another key finding regarding employment was that people living in the family home were supported by parents to identify and to organise work opportunities, while those living in personalised settings were mainly supported by their key workers in the same manner. Furthermore, both, parents and key workers stated their intention to match work opportunities with the person's likes and abilities.

Older participants (over 60 years of age) living in congregated settings were not expected to join the workforce (by their relatives), however, although there was not

support from family or key worker, one participant (Janet) was about to start a new job at 61 years of age.

| Table 4.19                            |   |   |  |
|---------------------------------------|---|---|--|
| Summary of employment across settings |   |   |  |
|                                       | Personalised Setting  | Congregated setting   | Family Home  |
| Employment                            | <ul style="list-style-type: none"> <li>• Key workers identified job opportunities</li> <li>• Seeking new paid employment</li> <li>• Voluntary work as mean to social engagement</li> <li>• Time off just after moving to personalised setting (coping with change)</li> </ul> | <ul style="list-style-type: none"> <li>• Elder participants were not expected to find any work opportunities</li> <li>• Person living in group home, her key worker had expectations for her to work</li> </ul> | <ul style="list-style-type: none"> <li>• Parents as organisers of paid employment opportunities</li> <li>• Employment as facilitator of social engagement and contact with people in mainstream</li> </ul> |

#### 4.8.5 Expectations for the future

This category is mainly based on the expectations for the future that key workers and parents had for the disabled person, rather than the expectation of the disabled person itself. Although the aim of this study was to explore the experiences of disabled people, prioritizing their narratives, the researcher considered that this category could enrich the understanding of the lives of disabled people across settings (see Table 4.20).

| Table 4.20   |   |  |   |
|--|---|--|---|
| Summary of expectations for the future across settings |   |  |   |
|  | Personalised Setting  | Congregated setting  | Family Home   |
| Expectations for the future                            | <ul style="list-style-type: none"> <li>Key workers were surprised by the persons' capabilities once out from the congregated setting</li> </ul> | <ul style="list-style-type: none"> <li>Low expectations from parents</li> <li>Limitation of potential</li> </ul> | <ul style="list-style-type: none"> <li>Concerns in relation to parental ageing/death</li> <li>Concerns in relation to living accommodation once parents are not longer able to provide</li> </ul> |

Therefore, based on their narratives, people living in personalised settings and in the family home had a more positive 'envisage future' than those living in congregated settings. However, the expectations were different. First, key workers of persons living in personalised settings expressed their disbelief when they got to witness the capabilities over the disabilities. For example one key worker (Lucy's) admired the resilience and the ability to embrace change, because after 40 years of living in an institution for people with ID the person supported was able to learn a variety of ILS and to have a positive attitude towards the future.

According to the relatives of those living in congregated settings, the future was not going to be any different than what it was. They considered that all possible achievements were limited to learning some basic ILS, not considering any further education, social engagement or community activity to enrich their lives; all was reduced to basic needs being covered.

Expectations from parents of those living in the family home were contrasting, in one case the mother was positive and expected only betterment and enhancement of the quality of life. While the other mother expressed that her son would always be 'held back' because of his limitations and being illiterate; clearly, she was unable to see

her son's abilities resulting in low expectations. Furthermore, parents expressed concern about where the person supported was going to live once they were unable to provide shelter for them. Key workers of those living in the family home had only positive prospects; indicating that even when they considered living in the family home as something positive, the person supported should have the option to move out to independent living in order to achieve more independence at some point in the future.

Overall, these findings across settings allow us observe that perspectives on the future development varied considerably across settings. The expectations that family and support staff has could potentially influence, first the support that they offer and second, the individuals' self-confidence and self-esteem, which eventually may be reflected in their success/failure. Therefore, in that sense, this could be a theme meritorious of further exploration in further research.

#### **4.8.6 Support**

All participants were supported by key workers through the ILS programme. However, there were some variations on the support provided as summarised in Table 4.21.

First of all, participants living in personalised settings stated that the process of deinstitutionalisation was challenging, and it would have not been possible without the support they received throughout. Nonetheless, two of the four participants previous to the successful move to a personalised setting, had a negative first attempt to move out from institutions due to the lack of support in getting prepared for the change. Both participants were given only one day notice prior to the move; as a result both participants were unable to cope with the change. One participant (Lucy) had to go back to the institution for people with ID after a couple of weeks living in the community, and the other participant (Jack), with MHP, had an adverse reaction to the 'dictatorial' notice and they had to cancel the move. Those experiences provided information about the lack of a programme to support people to be ready for the change, which is fundamental, especially considering that most people had lived in the institutions for long periods of time, and in some cases, for

most of their lives. Thus, as pointed out by participants, the transition should be gradual, progressive and supported.

Once living in the congregated setting, according to the person with disability, the support was good. Likewise, key workers expressed the empathy that they developed working in congregated settings, where they had the opportunity to get to know more the person and assist them in a one to one basis in comparison to when working in congregated settings.

For those living in congregated settings, the support from key workers was communal rather than individual, ignoring the capabilities of each person, which lead to over support. Likewise, their relatives did not express a willingness to offer support, rather the opposite; they expressed certain disengagement from their relatives' lives.

Regarding participants living in the family home, the findings suggested that parents not only covered basic needs, but were engaged in locating job opportunities for their children. However, their support was contradictory; on the one hand, they encouraged them to acquire ILS to reach independence and autonomy, while on the other they prevented that independence from being achieved by providing with 'everything', depriving them of the natural experience of doing it by themselves.

In general, all participants were supported in one way or another, but this study found three main aspects: 1) it is necessary to have a programme in place to support the transition of deinstitutionalisation, or even moving from one house to another, or moving from the family home to independent living. A 'failed first or second attempt' was not caused by the 'disability' of the person, but by the lack of planning and support offered by services; 2) family members should be better informed in order for them to offer better support to their relatives; and 3) support should not consist of only family and key workers but also the support of the whole community, as this is fundamental to achieving full integration and equal experiences to the wider population.

Table 4.21

| Summary of differences on support provided across settings |   |   |   |
|--|---|---|---|
|  | Personalised Setting  | Congregated setting   | Family Home   |
| Supports provided  | <ul style="list-style-type: none"> <li>• Personalised support emphasising individual needs</li> <li>• Emphasis on the importance of support previous and during the de-institutionalisation process</li> <li>• Help from staff to prompt medication</li> <li>• Empathy from staff (Key workers gaining a better understanding of disability)</li> </ul> | <ul style="list-style-type: none"> <li>• Routines shared by all residents, ignoring individual skills/abilities, leading (in some cases) to over support</li> <li>• Relatives only concerned about basic needs being covered</li> </ul> | <ul style="list-style-type: none"> <li>• Parental support covering basic needs</li> <li>• Parents seeking support from services for people with disabilities</li> </ul> |

#### 4.9 Conclusions

The above findings answered to the research questions earlier stated. They provided indications of the low rates of employment and voluntary work amongst both people with ID and MHP, and the relationship between being employed and levels of community activity. Finally, the participant's accounts illustrated their daily experiences, from their own perspectives and through them it was possible to gain a better understanding of the differences and similarities across the various living accommodations.



## **5. DISCUSSION**

### **5.1 Introduction**

The findings of this sequential explanatory mixed methods study are in relation to employment and community activity levels of people with ID and MHP. Furthermore the experiences of nine persons in employment situation were explored, distinguishing between the various settings they were living in. This chapter will discuss such findings in relation to the existing literature. Finally the chapter will conclude with a discussion of some limitations of this study, recommendations for further research and a brief reflection about the learning process.

### **5.2 Employment status and community activity**

The findings of this study support the results of recent studies and rates of unemployment provided by authorities in Ireland, indicating that persons with ID and with MHP experience salient high rates of unemployment (NDA, 2011; Gannon & Nolan, 2004). Previous research indicated that from the different types of disabilities, those with MHP were affected the most by unemployment (Marwaha & Johnson, 2004). This was also confirmed in this study's population where around 20% of participants with ID were employed against only 10 % of people with MHP, indicating that people with ID have slightly higher employment rates than those with MHP. Furthermore, the majority of people employed were living in personalised settings or in the family home. In relation to voluntary work, rates remained similar across both groups, the only difference being that those living in congregated settings were engaged in voluntary work the most, followed by those living in personalised settings.

In relation to community activity levels, findings indicated that disabled people who are integrated in the labour market have higher levels of community activity, meaning by this that they go out more, they undertake leisure activities or belong to social clubs in the mainstream. It was also noted that people living in personalised settings for longer than a few months had higher levels of community activity than the people living in the other settings. Further longitudinal research may clarify this matter.

### **5.3 Life experiences of disabled people across various living arrangements**

This section seeks to take a closer look at the themes which emerged from participants' life experiences in various living arrangements and to interpret those findings in relation to the literature discussed earlier.

#### **5.3.1 Environment**

According to the participants' perspectives and experiences, the living accommodations had noteworthy differences between one another. For instance, individuals living in personalised settings described the environment with positive adjectives (e.g. peaceful and private) and also mentioned feelings of happiness and satisfaction, in the same way as those living in the family home. This finding is in accordance with the findings by O'Rourke et al. (2004) on people living in the family home reported mostly being happy, although they may experience loneliness.

Furthermore, they had the choice to decorate their space as they preferred. Contrarily, participants living in congregated settings noted their lack of personal space, but most important of all, they expressed a strong desire to move out of those settings to independent living ('have their own place/ a home'), also noted in O'Rourke et al. (2004) findings.

Participants living in congregated and family home settings reported a feeling of security. This could be understood as a consequence of 'others' (staff and parents respectively) controlling their environments, limiting their opportunities to experience any natural risk taken task (Fitzsimons, 2012).

#### **5.3.2 Independence**

In the area of independence and independent living skills (ILS), this study found different experiences reported across settings, although all participants were part of a programme acquiring ILS. Those living in personalised settings and in their family home had more opportunities and were encouraged more to put into practice those skills in personal, domestic and social areas (e.g. showering, cooking, and using

public transport). In these settings there were no time restrictions. It is worth mentioning what Barnes and Mercer (2005) noted in this regard: doing daily routines in a society that is designed by and for non-disabled lifestyles demands greater time (p. 537). Thus, time constraints for people with disabilities in doing things translate to restrictions in learning and developing ILS. Those time limitations and the rigidity of routines mentioned by Mansell and Beadle-Brown (2010) were identified on participants' accounts living in congregated settings.

### **5.3.3 Empowerment, self-determination and choice**

A fundamental aspect of community living is enabling disabled people to choose where and with whom to live (Mansell and Beadle-Brown, 2010). This aspect was evident in those living in personalised settings who recounted how they chose the setting and the persons with whom they lived (Lucy lived with a female). Contrarily, those living with their parents and in congregated settings were not there 'by choice' (as Jack said). These accounts happening in the 21<sup>st</sup> century in Ireland, run counter to local policy, the National Disability Strategy and the CRPD, thus these findings confirm many of the concerns and complaints with regards to actually achieving 'choice and control over where and with who to live'. As stated by Verdugo (2012), something more than a treaty (CRPD), is required to guarantee that the rights of people with disabilities are being respected" (p.39).

### **5.3.4 Support**

The literature recognises the importance for people with ID and with MHP to have adequate support from staff in any type of setting (McConkey et al., 2004). This study contributes to emphasising this aspect, specifically in the support provided preceding the move out from congregated settings, as some participants highlighted being notified only one day in advance. Considering current national strategies addressing the de-institutionalisation process in Ireland, this study's findings provide, through experiences, evidence of the lack of adequate support and planning when

'notifying' people (both with ID or MHP) about the move to other accommodation across services. To understand the magnitude of this change for them, it is important to stress that according to the HSE (2011), in Ireland approximately 75% of people living in congregated settings have been living there for over 15 years. Therefore, the sudden 'announcement' goes against human rights; thus it is not only immoral, but illegal. What is more, participant's narratives suggested that in their 'first attempt' to move to independent living they were not involved in discussions about their future. A similar situation was documented by Hubert and Hollings, (2010) in a study in the UK examining the post-deinstitutionalisation experiences from disabled people; reporting evidence of violation of their rights despite they were "back into the community" (p.189).

In this study support was identified as essential in different situations, for example, those living in the family home were assisted mainly by their parents, whose support was both, a positive and negative element in their lives. For instance, it was good as they covered basic needs. However, they limited their opportunities to incorporate ILS into their daily lives, as their mothers did 'everything for him/her', preventing independence and their empowerment, rather than, in fact, encouraging it. More support from parents of those living in the family home was identified regarding employment and social inclusion as examined in following sections.

### **5.3.5 Social inclusion and social networks**

Being in contact with family is fundamental regardless of the living accommodation (McConkey et al., 2004), yet this study found that those living in personalised settings had minimal contact with their relatives. This was acknowledged by their key workers, who indicated that they wanted to help them with restoring their relationships with families, while participants did not mention their families at all.

Support staffs play a fundamental role in community activity. Felce and Emerson (2001) noted that staff that supported choice and offered opportunities to participate in the community resulted in greater community activity compared with unengaged staff. This was also identified in the current study as support staffs working in personalised settings also play a role in identifying activities and offering diverse

choices. Overall, key workers, particularly those assisting people in personalised settings underlined that the relationship between them and the person supported was strong and was built on trust. Moreover, this was possible because the setting facilitated them getting to know more about the person on a one to one basis, which was appreciated by staff.

However, this study's findings indicated some barriers to social inclusion in activities and also contact with people, which were also identified in other studies (Abbott & McConkey, 2006) related to community factors such as attitudes towards disability. Participants indicated the effect of stigma on them and the will to move again to a new personalised setting, as they aspired to not being perceived by the community as a 'client', but rather as a person. This keeps in with previous research which has shown that when disabled people perceive themselves as being stigmatized, they have negative feelings about themselves and as a consequence, their self-esteem gets affected and consequently, it affects their interaction with the community (Paterson, McKenzie and Lindsay, 2012). This may be one factor that affects the social interaction, as another finding was that participants made no emphasis on significant friendships or relationships across the various living accommodations. Although there was not one specific item on the questionnaire about this topic, this finding suggested certain isolation and lack of opportunities to develop meaningful long-lasting relationships.

### **5.3.6 Employment**

All participants in this study were part of the few engaged in paid employment or voluntary work. Key workers and their parents emphasised that employment was important so as to be engaged in the community, thus they were involved in finding job opportunities. Those living in the family home were helped by parents to locate potential jobs. What was interesting is that despite them being employed, parents wanted to find job opportunities that matched the interests of the person with disability. In this regard, Shah and Priestley (2001) pointed out that in older generations disabled people found jobs assisted by the family; however, based on this study's findings, this has not changed and family still play that fundamental role.

As noted by a participant's mother, it would be ideal that as a part of the person-centred planning, employment opportunities should be considered. However, currently there is nothing established in that regard and key workers assisting disabled people in this area are doing it primarily on their own initiative. For instance, participants who were living in personalised settings, who were assisted in this matter by their key workers who, besides finding activities in the community for them, also pinpointed work opportunities that were associated with their capabilities and interests.

#### **5.4 Limitations**

This study encountered some limitations, principally related to the sample. It is important to stress (as previously mentioned) that this is a secondary data analysis, thus certain aspects are out of the control of the researcher, specifically in relation to the sampling process. People selected for this study were part of an ILS programme, which provided them with beneficial experiences in comparison with other disabled people in the general population who do not receive them as in Ireland ILS programmes are not available to the whole population with disabilities. Furthermore, because the selection in both the qualitative and quantitative phase was not random, participants cannot be presumed to be representative of those populations. However, while this study has its limitations, it fulfilled its purpose of exploring the experiences of disabled people who are part of the labour market across the various living settings available to them in the 21<sup>st</sup> Century in Ireland. Likewise, results are comparable to other studies referred in the literature.

#### **5.5 Further research**

There are several opportunities for some reflections and further research based on this study. Thus, the following are some recommendations suggested for further research:

1. To randomly select services who are developing community-based alternatives to congregated settings, and not necessarily those who had been granted a fund. A study seeking to be representative of all services in diverse locations.
2. To use focus groups methodology to further explore the support that people with disabilities had received from services in the process of moving out from congregated settings, seeking to access insights into people's shared experiences. This would inform authorities about the progress and the faults that need to be reassessed and addressed. All this considering the changes in disability policy that Ireland is currently experiencing (at the time of writing). Aiming to be a successful transition rather than one focused only on reaching the annual targets set and ignoring disabled people's right to equal choices to others.
3. Further longitudinal research may provide greater insights into the support, opportunities and challenges that people with ID and MHP face once they had moved to community living.
4. Finally, based on the scant literature covering voluntary work opportunities for people with disabilities in Ireland, there is a need to investigate this area. Perhaps the significant gap in knowledge in that particular aspect is caused by the traditionally image of disabled people being in 'receipt' of help, rather than persons capable of providing help to others. The author believes that research in the area would be beneficial for people with disabilities, as well as for society.

## **5.6 Reflection on the learning process**

The completion of this study is the culmination of a learning process in many areas for the researcher's academic life. This study had stages, which advanced in complexity and demanded more experience and learning on a daily basis. There were two main challenges; the first associated to the use of secondary data as this created a number of practical problems some already mentioned on the limitations sections. Although accessing secondary information had drawbacks, it also was beneficial considering time constraints; it would not have been possible to access the

data that researchers of the wider study shared. The second challenge was related to time constraints as the amount of raw data provided from the wider study was large and the process of transcription was time consuming, so as the coding process using the constant comparative analysis; demanding more time than the previously envisaged by the researcher.

The overall experience however was deeply valued. In this study, not only were the research questions answered, but many more questions were generated in a more organised form and with more theoretical background than when first started this research process. Therefore, on reflection, that is the most important part of this research, the possibility to generate more knowledge, to create awareness and to seek to undertake research, this time generating primary data.

## **5.7 Conclusions**

In conclusion, this study covered the areas relevant to community living, paid employment, voluntary work and community participation. Furthermore, it provided details of life experiences from the perspective of the people with disability, which added to the understanding of their daily lives in the settings they live and enrich the growing body of research in the area. Some key findings were the connection between being employed and community activity, which may lead to further exploration. Likewise, it was emphasised the importance of support from parents and key workers in locating job opportunities. Finally, it was evident across the various living accommodations that the 'moving out' from institutions is coming about. However, as previously highlighted, the outcomes of this process will be determinate to a great extent by the support provided before and after the move, to facilitate not only their social presence, but their social inclusion. Undertaking research where disabled people are the main source of information allows them to express their desires and aspirations in life, gaining confidence from their achievements, being empowered by parents and key workers to achieve more, but most importantly, their voices have been heard, and this study sought to be a modest contribution to hear those voices traditionally silenced.



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## **Appendix I**

### **CRPD Article 19 Living independently and being included in the community**

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement ;
- b) Persons with disabilities have access to a range of in-home residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

Community services and facilities for the general population are available on equal basis to persons with disabilities and are responsive to their needs.

### **CRPD Article 27 Work and Employment**

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

- (a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

(g) Employ persons with disabilities in the public sector;

(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

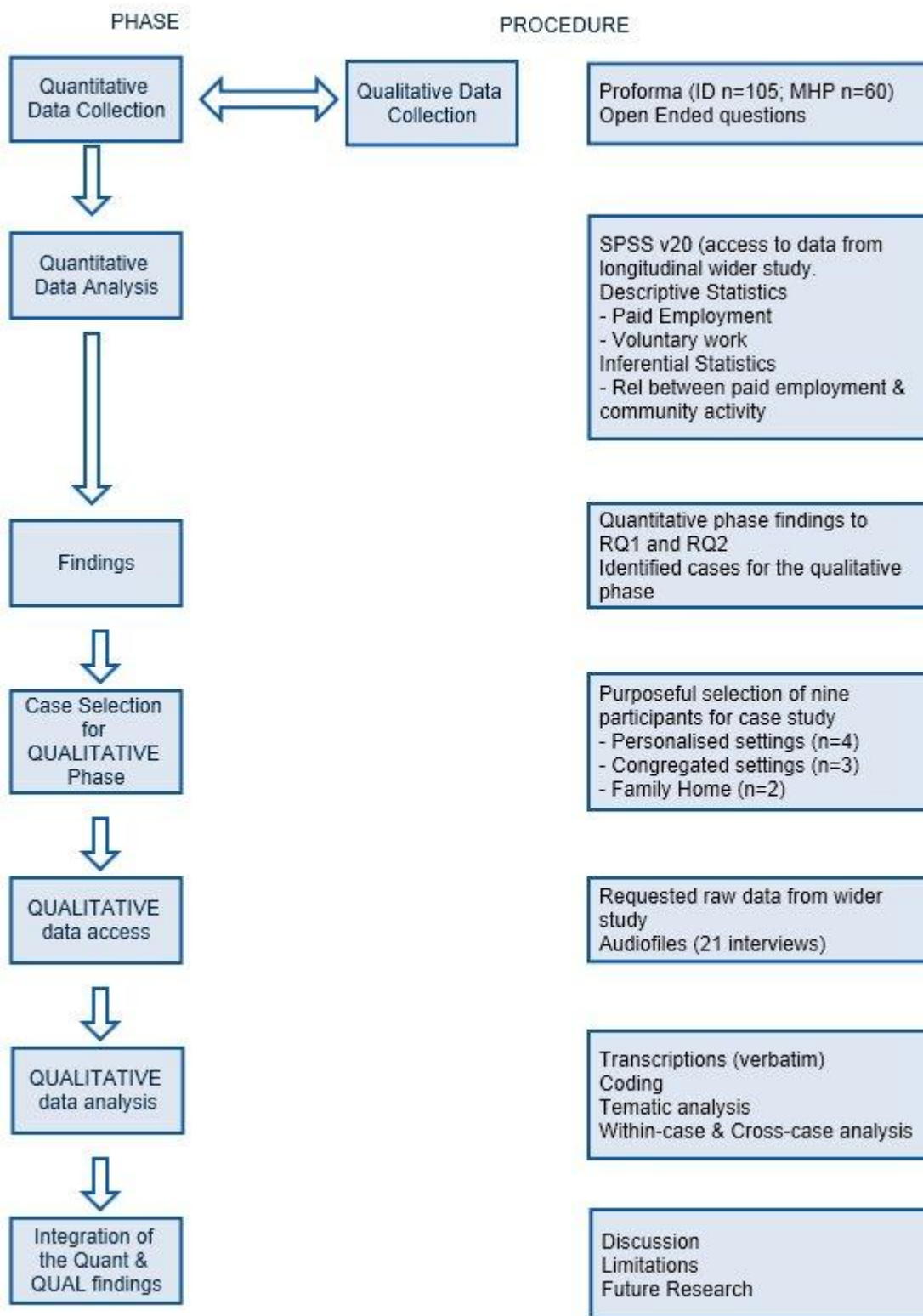
(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

## Appendix II – Visual Diagram of Mixed Methods Design



## Appendix III – Semi Structured Interviews

### Interview for the person with ID or MHP

#### *Part 1A: Interview for the people who had moved*

How is the new place working out for you?

What do you like about it?

Is there anything you do not like?

Is this the sort of place you wanted to move to? *If Unsure/No: What sort of place would you have liked? (Prompt: people live with; housing; location; support staff)*

How are things different for you now in your new place (*prompt: are you doing things you never did before*)?

In what ways did (name organisation) help you with the move into your new place – people like (Name key-worker/co-ordinator)?

What has been good about how they have helped you?

Is there anything that hasn't been so good – that you would like to change?

What more would you like them to do to support you in the coming months?

If you have support staff in your new place, how are they different from the staff where you used to live?

What would you say to other people who were thinking of moving but weren't sure if they should?

Anything you would like to tell me about the move?

#### *Part 1B: Interview for the people who had NOT moved*

Tell me about the place where you are living?

What do you like about it?

Is there anything you do not like?

Would you be happy to stay on in this place?

*If Yes/Unsure:* Why would you want to stay Ne?

*If No/Unsure:* What sort of place would you like to have (*Prompt: people live with; housing; location; support staff*)

What has (name organisation) been doing to help you in the past year – people like (Name key-worker/co-ordinator) – to help you to move into a new place?

What has been good about what they have been doing?

Is there anything that hasn't been so good – that you would like to change?

What more would you like them to do to support you in the coming months?

Anything you would like to tell me about moving to a new place?

## **Interview for the relative**

### ***Part 1A: Interview for people who have changed accommodation***

Where is your relative (N) living now?

How is the new place working out for N?

What do you personally like about it?

Is there anything you personally do not like?

How are things different for N now in the new place (*prompt: is N doing things N never did before*)?

What involvement do you have with N and the support staff and how has this changed since N moved?

How are the staff who support N in the new place different from the staff where N used to live?

Do you feel you as a parent/family have benefited from this new form of service?  
(*Prompt – give some examples*)

Looking back, in what ways did (name organisation) help N with the move into the new place – people like (Name key-worker/co-ordinator)?

Are there any ways you feel you/ the family could have been better informed or involved with preparations for the move?

How do you feel N has benefitted from this support?

What other supports does N get from the service (or other services)

What more support do you think N needs in the coming months?

Who do you think/hope can provide this support?

Is there any way you feel you/ the family could be better involved with supporting N?

What do you think the future could be like for N in say two years time?

In the future, what do you think would make N really happy?

What would you say to other families who were thinking of asking for this support for their relative but weren't sure if they should?

Any other comments you would make about the support N has been getting

**Part 1B:** Interview for people who have NOT changed accommodation

Where is your relative (N) living now?

In what ways is this place good for N?

In what ways is this place not so good?

What new accommodation is planned for N?

When is N due to move to new accommodation?

What has delayed N moving to the new accommodation?

How would you feel about N staying on in this place – not moving at all?

What have (name organization) been doing to help N in the past year with moving to new place?

How do you feel N has benefitted from this? (*Prompt: What have you done that has really made the biggest difference for N*)

Is there anything that hasn't been so good for N in terms of preparation for a move – that you would like to change or see done differently?

Are there any ways you feel you/ the family could be better informed or involved with preparations for the move?

What more support do you think N needs in the coming months?

How do you see the future for N (*what do you think the future could be like for N in say two years time?*)

Any other comments you want to make about the project and people changing their living arrangements?



## **Interview for the key worker**

### ***Part 1A: Interview for people who have changed accommodation***

So if I can just ask you, where is N living now?

And where did N live previously?

Community House? Okay and how is the new place working out for N?

Okay, what does N like about it?

Okay, is there anything that N doesn't like?

Ok and how are things different for N in the new place? Doing things maybe N never did before?

Great. Okay and what have the organisation being doing to help N, say in the past year with moving to the new place? Well, N moved before it, so what kind of services have been in place since the move?

Super. So it really is working for N. So what other supports does N get from the service other than the support N has in the house itself?

Yes, so during the day time N doesn't have any particular support?

Right but that is a different service to yours is it?

So what has been your role with N specifically?

Super. Ok so how do you feel ahm N has benefitted from your support? What have you done that has really made the biggest difference for N?

Super. And is there anything that hasn't been good for N? Things that maybe you would like to change for N?

So how do you see the future for N? What do you think the future will be like for N say 2 years down the road?

Okay and what more supports do you think N might need in the coming months?

So will you be able to provide any support that you think N might need going forward?

And do you feel other people, similar to N, would benefit from the type of, ahm, support you have been providing for N?

Yes similar ability level to N and so on.

And what reasons would you give for why it works for people?

Yes it is hard to imagine living your life like that isn't it?

So are there any other comments you would like to make about the support that N has been getting? Maybe you can add to the research?

That's right. I remember N with the tea and the coffee making and it was a big thing to N.

Yes I remember that alright, a gentleman. So turning to you as a support worker, in what ways if any has your role and the nature of your work changed in the new setting? Would you have been working in the residential setting at any stage?

So you came into this role?

And would you have any experience of working with people in residential settings?

So how do you feel the role, from your perspective, how is the role different now to what it was before?

And in what way if any do you feel you have benefitted as a staff member from your involvement with this project to help people change their living arrangements?

Yes. So for you, job satisfaction, morale wise that kind of thing?

And what does that do for you, the buzz?

Ok are there any ways in which it is not been good for you? Any improvements on ways you can make things better for yourself? Now think of you as the focus person in these questions.

And for you then as a person working in the field, do you think that is a good thing for you or a bad thing for you?

You are still fairly new to it?

So to what extent do you think that management is behind the project?

Why would you say that?

Yes so you feel well supported?

Have you any other comments you want to make about the project and people changing their living arrangements?

**Part 1B:** *Interview for people who have NOT changed accommodation*

Where is N living at the moment?

And in what way is this accommodation good for N?

In what ways is this accommodation not good for N?

What new accommodation is planned for N?

And do you know when N is due to move to new accommodation?

And do you know what delayed N moving to the new accommodation?

Do you think N would be happy to stay on living here?

And what has the Service been doing in the past year in helping N move to a new place?

What has been your role in preparing N for a move?

How do you feel N has benefitted from your support?

Is there anything that hasn't been so good for N in terms of preparation for the move?

So anything you would like to see done differently?

What support do you think N will need in the coming months?

Will you be able to provide the support?

How do you see the future for N in say 2 years time?

So turning to you as a support worker, so you feel that the role and nature of your work has changed in the past 12 months?

And do you feel that with people moving that changes your job?

Do you feel you have benefitted as a staff member from your involvement with this project to help people change their living arrangements?

Is there any ways it hasn't been so good for you?

Do you feel that other people similar to N would benefit from the type of support you have given N?

And do you feel in terms of your role as key worker do you feel other people similar to N would benefit?

And what reason would you give?

To what extend do you feel that management is behind this project?

Is there any other comments you want to make about the project and people changing their living arrangements?

## Appendix IV – Employment and Community Activity

### *Employment*

Are you in paid employment? No  Yes

### *Voluntary work*

Do you undertake any voluntary work in the community? Don't know  No  Yes

### *Community Participation*

In the past four weeks have you done any of these activities outside of the services?

| <b>Activities</b>  | <b>No</b> | <b>Yes</b> |
|--|-----------|------------|
| Gone to pub, café, restaurant?   |           |            |
| Played sports, swimming, fitness classes?  |           |            |
| Attended church, mass?   |           |            |
| Been to cinema, a concert, sports event?   |           |            |
| Social club-indoor games and crafts?   |           |            |
| Dances, discos, parties, celebrations<br>(such as birthday parties, christenings, weddings?) |           |            |
| Short courses, such as computer classers?  |           |            |

## Appendix V – Sample Transcriptions

### Example of the transcribed interview with the person with intellectual disability or mental health issues

Pseudonym: LISA

Living arrangement: Family home

Informant: person supported

Date of Interview: February 2013

**Q. That's excellent, so, you said, you haven't lived on your own. But what has ahm, is it your mum helping you and what is she doing to help you to move to your new place?**

You mean my..?

**Q. 'X Mother's name', your mum, how is she helping you to move to your new house?**

I am not moving to a new house [ok]. Do you mean that..? [The apartment?]

No no no, no apartment, it is a place that I have to myself. [yeah, the place you have to yourself] Yeah, in the house! [Yeah, that's it]. Yeah, she told you about the, amh, the place in the house that I just have for myself?

**Q., would you tell me about that?**

Well yeah, I have the big screen TV and my bedroom is at the other side.

**Q. And, who helped you to move to your new place? Are you moving yourself yeah?**

Yes, I am moving myself, yeah.

**Q. And what do you like about having this new place to yourself, tell me what do you like about it?**

Well, the TV you know.

**Q. Yeah, you like TV?**

Yeah

**Q. Is there anything else you like about it?**

Other people coming in, other people coming to watch TV, but I can just watch it by myself cause I can have one of my own.

**Q. Ok, that's great you have your own TV. Is there anything that you haven't liked or that you would like to change in the space that you have?**

Well I'd like to change the light

**Q. The lights? What is wrong with the lights?**

Well, nothing I would just like everything in my room changed, like the wallpaper and all but I would just like to change the light.

**Q. And what sort of lights would you like?**

I don't know what kind of light.

**Q. And okay uhh, what uhn, okay so you just living there at the moment. Sorry, some of these questions wouldn't apply to you because they are for people who moved for a long time, so ahh, So, who helped you find this place... to live?**

Well, it was in a house, you see, and doctors and my bedroom used to be my mom's office. But she does not use the office anymore.

**Q. Okay, and, you have your own front door? That you go in or you go in through the house?**

I go in through the house.

**Q. Okay. And, ahm, how are things different for you now living in that space? How long have you lived there for?**

Uhm, I don't know, uhm, 2 or 3 years? I don't know.

**Q. Very good, okay that's great.**

Or 4, uh I don't remember.

**Q. That's okay, that's no worries uh, so what would you say to other people who are thinking of getting support to move like 'x place' or 'outside who is going to come and help to teach you some skills about budgeting and on living. What would you like to learn?**

I don't know umh.

**Q. Okay, that's okay, and ahm, what would you say to other people who are thinking of asking for support to move in by themselves but they weren't sure if they should. What would you say to them?**

Amh

**Q. Would you say it was good?**

I would say it was good, yes.

**Q. Yeah, and you would tell them they might should? They should move?**

Yes

**Q. Okay, very good. Okay, and, have you a support worker Lisa?**

Support worker?

**Q. Um huh!**

What is that?

**Q. It is a person like a key worker? It is a person that you like, a person that you kinda report to. I think your mum, your mum may do that does she? She teaches you new things and uh, you meet her regularly.**

Well, I am 20, mm, 20 years old I do most things for myself

**Q. Uh, that's great, that's perfect**

Just like, I know how to tie my shoes.

**Q. Uh, well done, that is fantastic, that is great. And there is anything you've learned recently? Do you cook in the house?**

No.

**Q. Okay, perfect. Okay. That's the first part, anyway done Lisa. Okay, thanks a million for that, that's excellent.**



## Example of the transcribed interview with relative

Name: LISA

Living arrangement: Family home

Informant: Relative (Mother)

Date of Interview:

**Q. Ok 'X Name' Thanks a million for being here today and thanks for giving me your time, ahm, and just to let you know that everything that we say here is confidential, ehm, and for the purposes of the interview, I am just going to allocate a code, if that's alright and the code is a little bit long, but anyways is 'X Code' Are you alright to start?**

Yeah

**Q. So, where is "Lisa" living now?**

She lives with us at home, with her family

**Q. And in what way is this place good for Lisa?**

Ah, she gets everything done for her. (laughs) Mhm, well I mean, obviously she is safe and secure, she is only 21 so ehm, I have an older boy who is still living at home as well so it is not awfully unusual really, **[okay, okay]** umnh, but I wouldn't like is that just because she has an intellectual disability, is that she would never be able to live anywhere else, and so it was my interest in the project really was to start working on getting Lisa more independent **[okay]** at home , you know, with if she wants to a view to moving and living elsewhere at some point in the future **[okay, okay, ok]**.

**Q. Ehm, ehm, I suppose, eh eh I am just gonna, kind of, I am going to skip some of the the questions 'X Name', but I suppose I am going to look at this one as in, in what ways do you think that home, I suppose, or this place is not so good for Lisa?**

Well, the same thing that I said before, she gets everything done for her. Yeah, emnh she is inclined to be, you know, just like to have things done for her, like to get quite relaxed about everything, not really to want to, you know, do things for herself and there is a temptation you know, you kinda look after her. I would of look after her

from, you know, since, you know, she was very small, emhn, so it is very hard to get out of the habit and to try to help her to do things for herself. So uhm and harder for me than I think as it would be for somebody as she is more likely to listen at somebody else if they say to her it would be a good thing if you were able to do things by yourself or to cook yourself a meal or something about.. Me, she will just ignore or whine and give out or whatever, so it's harder so, umnh But I mean it obviously she is happy at home and she is happy being with her family. In some ways I think it keeps her quite isolated. Uhm, you know, she wouldn't have much in the way of friends or, ehm you know, uhm she she goes, she spend time with people in her day placement but she would never speak of anybody as being a friend. She'll be her friends or people that would know their names would be staff, more so than friends and, she used to have friends on the road and she referred to people as being her friends. Then, of course, as those girls got older ehmn, they stop calling and eh so so yeah,; but I mean she doesn't seem to mind not having friends, but it would be more me thinking, you know, she is quite isolated here in the house, and she just has her family basically, so I suppose that would be a downside. I am not really sure, whether if she was living elsewhere it would be any different.

**Q. Yeah, uhm, how do you feel about Lisa staying on at home and not moving at all then?**

Well, I suppose there will come a time when her dad and myself will be older and she could be my age and still living at home so I think that wouldn't be such a good thing because you know what happens when we are gone then, you know does she stay living alone which she's never done in her life before, would she be prepared for that? Probably not, so so, emh I think she always talks about wanting to maybe move to an apartment with some friends or something like that. Ehm, now that is probably something that she picked up from the television rather than something that she actually really would want to do. But I think she does need at some point over the next, you know, number of years, I suppose the opportunity to at least know she is able to, to live independently and for us to know that she is able to live independently, even if it's not very far away.

**Q. Yeah, I know, I know uhm what has the "x Service" been doing to help Lisa in the past year?**

Well I can tell you about the practical things and I could tell you what I think that's what is the most important thing, which is that she thinks differently about things now, **[okay]** you know. She knows more or she is happier to try new things **[okay]** that she used to be. She is more confident in being able to do things. Even if it's I suppose the first thing I would have noticed was that she said 'Ummh I am going to go over to the shops', which is only across the road, so it is a short walk 5-10 minutes' walk but it is just cross the main road. Uhm and she would always in the past, before she was involved with "Service" she would have said, would you drive me over to the shops? **[okay]** Or can we go to the shops.**[okay]** Now if she wants to go to the shop she just gets up and goes by herself **[alright, okay]** and uhm, you know so. I mean, the first time she did it I followed her **[interviewer laughs]** just to make sure she was getting across the road safely **[okay]** but uhm that's just me and hiding behind of a car so she wouldn't see me because I didn't want to knock her confidence, but you know people in the shops know her and talk to her **[yeah]** and uhm so she is quite happy to go over and do that now, you know and so it is just things that she wants to do, now she likes to go down to the centre, she likes to go to "restaurant" and get a meal and she can get the bus down there now and go to 'X Restaurant', she does that by herself, ehm, she is actually happier by herself than this ahm another person on this project who she has gone out with to the cinema and to "x" and you know, to be quite honest, she would be just as happy to be by herself doing that, **[okay]** but but I suppose the thing about it is that she will decide,**[okay]** that's what she has to do on Saturday and she will go often and know that there is a movie on or whatever and that she wants to see and she is able to do that, and there again I followed her the first time she did that ehm.. and watched her paying for her as she went to the cinema and so once she was in there I knew she was alright **[yeah]** so I was hanging around the centre waiting for her to come out again. But yeah, I mean you know, you are going to be worried for stuff like that but ahm, yeah. So, on the other practical things like she can make things for herself now, you know she wouldn't starve. I mean it might not be a full meal **[yeah, okay]** but she can cook spaghetti, you know, she can heat up things **[yeah, yeah yeah]** and use the microwave and so she is definitely making more of a stab at cooking and uhm she'd do a little bit of house work now, which ahm she needs to be encouraged about, but she can do it **[okay]** and she's sort of learning that she can, but where is previously she would be like I cannot do it **[okay]**. I can't do any of this this and now

she knows cause she is done it a few times and she knows that I know she can do them so.. yeah, so that's another practical..

**Q. How do you feel that Lisa has benefit from all the support?**

Well, I just probably covered most of it, ehm. She is a happy person really, you know, so it is hard to say uhm oh, she is much happier now, because she's always been a happy person and sometimes she doesn't want to do the things that you are saying 'Lisa today is the day you have to take the bus by yourself' or whatever and she would say, uhm, 'I am a little bit tired, would you drive me today' or something, you know, but that's not her being unhappy that's just her way [yeah, yeah]. Uhm, so but ehm, but I think it has ehm made a difference to how she thinks about herself and I think that's important [mm, okay, okay, okay].

**Q. Uhm ehm, is there anything that hasn't been so good for Lisa in terms of preparation for the move, that you would like to change or see done differently?**

Ahm, not sure about preparation for the move, uhm ehm, you know there is an awful long way to go be like she wouldn't really be terribly aware of keeping herself safe and secure in a house if she was by herself, like making sure that the locks are locked and things like that just so are lots of areas that could be improved upon before she kinda get to that stage, uhm but uhm, I suppose uhm, what I would like to see uhm, work being done on now is more kinda more of the same but just take it a little bit further like increasing uh, you know, enabling her to go further afield and feel safe with the bus training cause she can do certain areas now, just to give her more choices so, if she wanted do different things, like, she can know how to do those things and the work aspect, the main thing that I have that I've always has a dislike for is when a person has intellectual disability and you know, you get an assessment and you are told 'your child has a moderate intellectual disability' and that's like a label kinda thing, which indicates what pathway you are going to take and you will never get off that path; no matter what you do, you know so she is availing of "x services" and she is in "y service" as a day service and she likes it and all of that is fine, but I wouldn't like to be sitting here in 20 years time and saying she is still in "x permanently, so uhm, that's why she does one day a week, am, it is only an hour that she does in the local shop but I had to organise that for her, you know, it is not something that has been thought of by the service that the agency that gives her her

day service as being a way to go, you know, as far as I am aware anybody who is attending those day services who is working elsewhere as well has been organised by family [okay, okay] or the people themselves so I would like to see it as part of the person-centred approach that would, you know, push more towards where 'what else what can this person do?' Not 'how can we manage this person keep them amused for the day', you know, I know it is not as bad as all of that [I know, I know] and you do good things, but uhm, so Lisa, she likes children and uhm, my idea at the moment is to organise for her to get some work experience to start with, in a preschool [okay, okay] or crèche or something like that and, you know, maybe for some work to be done to get her ready for that and develop the skills [yeah] and that she would need and then, it is something that we are thinking of organising now ourselves where I work so, uhm, but I would like her to get involved in that and I think the more mainstream, uhm, employment opportunities that are for her, the easier or the less likely it will be that she'll just remain on this one path [I know, I know] or she'll never get off, you know [yeah, uhh, yeah].

**Q. Uhm...are there any ways you feel you or your family could be included more, for the preparation for the move?**

Uhm, yeah well with I know we talked about this particular project here in 'X service' where there is not obstacle as us being involved in that particular project that as we want to be, in general, uhm yeah, definitely I mean, there is very little in the way of consultation with parents or as I said before such as developing person-centred plans which, to me a person-centre plan it's not something that is done to a person, you know, it shouldn't be as this is the agency and now we are going to have lip service to having PCPs, you know, but it should be more it should be more about, you know, somebody saying to Lisa what is it that you want, who do you want involved in helping you to make these things happen, you know, do you want somebody from 'X Services', do you want somebody from 'X Service', do you want your mommy or your bother to..who is it that you want there and, you know, and that will help you to, uhm, and I think that is one way that families can be more involved in the services [yeah] and the planning of the services [yeah] and I know that one of your questions at the end and that I answered was about the individual funding and,

you know, I think that's definitely one way, I have some concerns about it as well, but I think is one way of giving the ability, the choice, back to the people who need the service rather than an agency [yeah] making decisions on behalf of somebody else [yeah].

**Q. Yeah amh, what more support do you think that Lisa needs in the coming months and you kinda touch that a lot but..**

And I've probably written it there where I answered the question as well, ehm yeah I mean It's, what she needs is not something that just she gets and then is over with and then is done, it's a process so it's on-going work, amh, in what we've working on already [yeah] and as I said, I mention some of the areas in relation to work, ahm, employment opportunities and training opportunities and things like that ehm, that would come from that I suppose when she gets to that point [yeah] and then sometime in the future, I suppose something I suppose a way maybe to work towards kind of removing her from the family home a little bit like getting her used to being away by herself it's it's trips or holidays, or you know, something that she will do with other people which she hasn't really done so, those kinda would be the main areas I suppose that I have been thinking.

**Q. Emh, how do you see the future for 'Lisa'?**

Well, if nothing changes, it will, we could be sitting here in 20 years time I think pretty much the same. If things can change and if the likes of these kind of independence projects can continue, you know, I would see her, hopefully, in at least at two-three day mainstream employment situation where she would come into contact with people who don't have intellectual disability as well as the people that she does already know, ehm, maybe get opportunities to develop relationships, you know, in some ways is not surprising that she kind of, ehm, has difficulty with, ehmm, knowing what's might be expected from her from a social point of view because she doesn't ehm, she doesn't have any example to follow where she is , so if she was in mainstream more, I think maybe she'll learn a little bit more, I mean it's small little things like, you know, she tends to hum away to herself when she is by herself and sing little songs, and people would sometimes other people with intellectual

disabilities would sometimes say 'stop singing you are annoying me' and she doesn't understand why she cannot be singing, you know **[okay, okay]**, so, you know, all this kind of rules of society I suppose that she is not really aware of, you know **[okay, okay]**, uhm so yeah.

**Q. Ehm, any another comment that you want to make about the project and people changing their living arrangements in general terms?**

Couldn't speak highly enough of 'x service' and what Lisa has got has made a huge difference to her and to us and I would say that as well that even though I kind of work in the area of disability myself, so I have a good idea. It is very different when you are talking about your own child **[yeah, absolutely]**, and you know and I know that this is where that I would be inclined to, you know, be concern about her safety and her well-being and, you know, the example of follow her around the place and all of that you need to get to a point yourself where you can have confidence **[yeah]**, that she is able to do those things by herself, ahm so eh, I think the idea of anybody no matter what their disability is, whether is physical or intellectual being able to have choices about what they do in their life it's what's important. I am not saying that everybody has to live independently or to live alone, I think it's about what people want and and that you are not automatically assuming that you know what's best for somebody else, you know, but that ehm, the person and the person themselves, because I know this from Lisa needs ah a bit of help around understanding what they can do so you can't you know, it's not as simple as just saying 'do you want to live there or there', you know, oh, I'd live there, but if that's the only thing they ever done, then that's what they are going to say **[okay, okay]**, so they have to be helped to imagine a different kind of life as well so. But anyway, long may it continue, that's all that I can say.

**Q. So, can I just say thanks then, thank you for giving me your time.**

Thank you

**Q. And I wish you the best for the future.**

Uh huh, thanks very much.

## **Example of the interview with key worker**

Pseudonym: LISA

Living arrangement: Family home

Informant: Key worker

Date of Interview: February 2013

**Q. Ok 'X Name' Thanks again for being here today and giving me your time, ahm, and just to let you know that everything that we say is confidential, ehm, and for the purposes of the interview, I am just going to allocate a code, if that's alright and the code is 'X Code' and just to clarify before the beginning of the ehm the interview. Lisa has not changed accommodation?**

No, she is still at her home [okay]

**Q. So, where is she living now?**

Well, she is living at home with her parents and her brother in 'X address'. [okay]

**Q. In what ways this accommodation is good for Lisa?**

Well, it's her family home and she is living with her parents and she is, ehm, learning skills to become more independent for when she does move [okay, okay]

**Q. In what way is this accommodation not so good for her?**

I say probably with responsibility, she probably she doesn't have enough responsibilities for when she does move out, you now, managing bills and stuff like that. She is learning the basic skills at the moment; now, she has her own side of the house and the building extension built so that's Lisa's side. She has her own bedroom, own bathroom and a sitting room down stairs and upstairs she has her own bedroom [okay, okay], so it is a very well, good set up for her.

**Q. Okay, okay so, I am going to skip the next three, because it's kind of, you know, what kind of accommodation is planned for her and there is nothing planned at the moment. What it is is that the 'X Service' is doing is kind of enhance support for Lisa, you know, kind of improving preparation for the move, I suppose in the future. Do you think that Lisa will be happy to stay in her own home and not move at all?**



Of course, yeah, is not... don't mention it to Lisa at the moment, she doesn't want to move out, she is content and happy in her home, yeah, so **[okay, okay]**

**Q. What has 'X Services' then being doing to help Lisa in the past year?**

Well, we would met with Lisa last December and Lisa's first goal was to travel to work independently because she relied a lot on her family and her brother as well; so just for her to become more independent, that was her first step. So, with the support of the bus training and be walking to the bus stop, identifying the stops bus and that, which is the safest to get on, uhm, what she does on the bus, prior to press the bell, getting, what stop to get off, walking to work. So, it would be support all around that, amh, that would have been for a couple of months and then we would have stepped to the background and shadowed Lisa doing it herself **[okay, okay]**. So I'd say about 8 months of that was just working on travel training. Now, for the next step and that's Lisa going to the post office to collect her own money herself. She doesn't know which to keep it on her purse herself and how much she has to hand up. Ahm so, it is all around the value of money now and that we are working on **[okay, okay, okay]**.

**Q. And what is your role 'X Key worker's name' with Lisa?**

Well, my role would have been to support Lisa in her next steps in what Lisa wanted to do, so I would being going out and doing travel training with Lisa, I have been the link between Lisa and 'X Service' and going out and meeting with her and her family and see what type of support she needed. Identify we identified different groups and organisations out there that ran art classes and that, but Lisa didn't want to be part of them; Lisa knows what she wants to do herself.

**Q. Okay, okay, how do you feel that Lisa has benefited from your support?**

I don't think she would be travelling to work independently if she hadn't had the support on the ground, someone apart from a family member going in and doing this training with Lisa cause it's too hard for families, the bickering and she knows she can get away with that one, **[okay, okay]** then an outsider coming in so it is easier and it's easier for the family that they don't have to worry about – and that Lisa is getting on well with the support.

**Q. Is there anything that hasn't been so good for Lisa in terms of, you know the work that has been done that you would like to change or do differently?**

I'd say Lisa works in 'X' it's one of the workshops in 'X Service for disabled' and I think, sometimes she doesn't like to take off works, as she calls it, to work more consistently on different areas, to work around Lisa's schedule and some days she's identified these days of rests, so you can't go in to her on those days, so that has been a little bit difficult at times **[right, right]**.

**Q. What more support do you think that Lisa needs in the coming months?**

Well, the same support on the ground of us going to the post office with her and shadowing her and supporting her, encouraging her, and she has the potential to do whatever she wants to do now, but it's just having the support there to put things in place.

**Q. Would you be able to provide this support?**

Hopefully if the project is extended then I would, yes.

**Q. How do you see the future for Lisa?**

Well, Lisa, I wouldn't worry about Lisa, towards other participants, Lisa will get by. She'll go out and she doesn't, she doesn't see things that other people would be worried about, and that. She goes out and if she wants to go to the shops, she goes to the shops and that's it, not like, she doesn't take in her whole environment around or what's going on at times, but I wouldn't worry about her. Maybe if we build her steps up towards eventually moving out, but it would be a couple of years **[yeah, okay, okay, okay]**.

**Q. So now we will turn to you in your role as a support worker, In what ways, if any, has the role and the nature of your work, the work changed in the last 12 months, since the start of the project?**

Well, probably as when we were coming on, we were told that it would be totally different what we were doing. It just has gone into so many areas now that you couldn't find a job description for it. You have to do everything that the participant, cause they only have a year and it's not fair to say, now you cannot do that or my

hours are done. You have to be there and let the person lead the way, and be open to change so, yeah, it has changed.

**Q. In what ways, if any, do you feel that you've benefited as a staff member in your involvement with this project?**

Well, I think it's working on the ground one to one with individuals, gains a lot of experience on that, and knowing that each person has the potential to become who they want to be, not just sit in workshops or sit in different places. That each person once they have the support on the ground and go at their pace and their level, that they can achieve their dreams **[okay, okay]**.

**Q. Are there any ways in which that has not been so good to you?**

Ehm, again, I just say for the outside for the outside supervision, now the management that has been behind it, as well as, I'd probably say with uncertainty of the funding. Cause you sometimes can give people false hope, by saying, they get anxious about two months before the projects coming to an end and we don't know and we're explaining it to them that we don't know either and they become very anxious and then, the funding, going back to last November, it was extended to February, and then in January people are getting anxious again and last minute again we were extended so, that uncertainty isn't great.

**Q. Do you feel other people similar to Lisa would benefit from the type of support or service that you've provided to her?**

Oh, definitely, I think a lot of people need support on the ground, in everyday life. ahm, people want to do basic things and they probably, might be things we take for granted **[yeah]** and they just need support in doing that, once they get the support then they are able to manage themselves **[okay, okay]**.

**Q. And you answered this question already, but it's in sequence so, what, to what extent do you feel that management is behind this project?**

Ahm, a 100% "X Name" is actively seeking funding all the time. Here in our centre we have a maintenance team and all the rest of them would be mostly admin or a radio show **[okay]** but this is the only project that's really out there and linking people in with other services, and identifying their needs, the maintenance seems to go out

and the most important for people is have a chat, they are isolated. Whereas, we are the only ones as part of this centre here, to actually go out and work one to one with clients for their needs.

**Q. Any other comments you want to make about the project to people changing their living arrangements?**

Well, again, I'd highlight about the year project that it's not enough time to build up a relationship with some clients, ahm, and if parents are not open, that your only getting that done and the project it's winding down and to be longer than a year.

**Q. Okay, can I just say thank you. Thank you for all your support, for me coming on site and can I wish you all the best**

## Appendix VI – Codebook

| Code         | Description   | Example   |
|--------------|---|---|
| Institution  | Stakeholders describe or make a comment about the characteristics of institution.   | <i>“I want to be in my own house...I am not very happy (in the institution). The centre is too old. I want to go into my nice house”,</i>   |
| Choice       | Participant having the opportunity to make choices on their own.  | <i>“the people that live here aren’t here by choice, including myself... It’s not an intentional community, it’s a community of people who would possibly rather be somewhere else but they don’t have the choice because there isn’t anywhere to go”</i>                                   |
| Stigma       | Stakeholders refer to social attitudes that reflect differentiation, discrimination, stereotypes, ‘labels’ in relation to their disability or sel-stigma. | <i>“...there is a lot of stigma attached to, you know because you are in the psychiatric services, doesn’t matter what you suffer from whatever, there is a lot of stigma attached to it, then eventually you lose a lot of dignity self-dignity, self-love I suppose you know” (Jack).</i> |
| Freedom      | Liberty of the person, no feeling of restrain.  | <i>“I love it, I have more freedom here. I can do more things here” (Tom)</i>   |
| Emotions     | Experience of feelings associated with their living arrangements  | <i>“[F]irst, I used to be terrible nervous about [getting] money on my own, now I get used to it, now I can do it myself” (Patricia)</i>  |
| Expectations | A belief that someone should/ will achieve something  | <i>“Unfortunately he is going to be 62 in March and I can’t see his life changing too drastically. He is not going to get a job obviously but it is a case of him having a more relaxed life” (Pau’s relative).</i>   |

|                         |  |  |
|-------------------------|--|--|
| New skills              | Any acquired new skills as a result of training  | <i>“I do the washing up and drying up and setting the table ...and I am able to shower myself, (Janet)</i>   |
| Employment              | Being active in the workforce, currently working or planning to work   | <i>“I haven’t been at work a lot, I have been ringing them telling them that I am moving and I have lots of things to do. I need a little bit of time and space for myself”</i>  |
| Community activities    | Any activity that takes place out of the place where they live, and have the opportunity to interact with people (e.g going to the cinema, going to the pub, to a restaurant, etc.)                        | <i>“I can do more things [like] walking to work, exercising in the gym...I do Thai Chi on a Tuesday now” (Tom)</i>   |
| Disablism / Ableism     | Believes/ thoughts that people with disabilities are not capable to do certain things.   | <i>I think she has a fairly good quality of life at the moment and that is all she is ever going to achieve. You just can’t hope for miracles.”</i>  |
| Confidence/ self-esteem | Feeling to have the ability to do what the person wants to do. / Feeling of pride for doing something, have something  | <i>“I think she will do very well, she will gain more confidence...she will do very well in a small setting” (Janet’s key worker)</i>  |
| Social engagement       | the extent to which an individual participates in a broad range of social roles and relationships. Avison, McLeod and Pescosolido (2007)   | <i>“she likes ...meeting the neighbours...she actually met the girls next door herself [when] she was out having a cigarette and they came along and they started talking... she kind of started a friendship with the neighbours” (Lucy’s key worker)</i>               |
| Inclusion               | It refers to the process whereby every person who wishes to can access and fully participate in all aspects of an activity of service in the same way than any other member of the community (EASPD, 2012) | <i>“He’s got a sense of support in the neighbourhood, a sense of security. So far so good, it is working out very well for Tom...Tom likes just the whole community and being part of the residents association and the street that he lives on.” (Tom’s key worker)</i> |

## Appendix VII – Research Ethical Approval

Dear Genevieve,

Please see below the recommendations of the Ethics committee regarding your application which was considered at the meeting held on April 15, 2013.

Status: Approved.

Please note that you have received a copy not the original audio-recording and that you are conducting secondary analysis on this copy. You must liaise with Dr Edurne Garcia to provide a confidentiality agreement in relation to the audio-recording for the Genio project documentation. Please clarify with Dr Garcia the exact steps to be taken in your transcript data retention and destruction process.

Kind regards

Jennifer

Jennifer McSweeney

*School Administrator*

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## Appendix VIII – Confidentiality Agreement

I, Genevieve Ruiz O’Sullivan, student of the M. Sc. in Disability Studies in Trinity College Dublin, agree to maintain full confidentiality in regards to the data received on July 2013, through Drop Box by Dr. Roy McConkey, the lead researcher of the study: “An Evaluation of personalised supports to individuals with disabilities and mental ill health”; and by Dr. Edurne Garcia-Iriarte, the Coordinator of the MSc. in Disability Studies, who granted the access to this data for a secondary analysis study for the completion of my dissertation project.

Data consisted in the following:

- -Audio-files: Containing 22 recorded interviews.
- -SPSS Dataset.
- -Unpublished Reports from the study mentioned above.

Furthermore, I have:

1. Transcribed verbatim the audio-files.
2. Anonymised and omitted any information that could lead to identify the participants’ identities.
3. Assigned pseudonyms when adequate.
4. Stored audio-files in password-protected files on personal laptop.

Furthermore I agree:

1. To return verbatim transcripts of the 22 interviews to Dr. Edurne Garcia-Iriarte via email. This e-mail will be deleted after confirmation of receipt.
2. To hold in strictest confidence all information in relation to the study and in particular, the identifications of any individual.
3. To keep stored all study-related materials described above so as the transcripts in password-protected files for a maximum of two years following the completion of my dissertation study, after which they will be destroyed.

All procedures will be upheld in accordance with the Data Protection Guidelines on Research in the Health Sector 2007 and The Trinity College’s Policy on Good Research Practice, 2009. I understand that to violate this agreement would constitute a serious and unethical infringement to the informant’s right to privacy.

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Student’s signature  
Genevieve Ruiz O’Sullivan  
Date\_\_\_\_\_

---

Coordinator M.Sc. in Disability Studies  
Dr. Edurne Garcia Iriarte  
Date\_\_\_\_\_



## **Appendix IX – Background information for Personalised setting Case Study**

### Patricia

Patricia is an Irish female of 51 years of age with ID. She was living independently in a two bedroom apartment at the time of the interview (December 11<sup>th</sup>, 2012). Previously, she lived with another two females with intellectual disability in a community house. Her key worker informed that before moving to personalised setting she was 'over supported', whereas in the new house she is more independent. It is worth noting that during the interview, Patricia was distracted with the audio recorder, as noted by her key worker, who was with her at the time of the interview. Patricia answered some questions with monosyllables.

At the time of the interview she was nervous as her key worker identified as she was putting too much attention to the audio recorder. She is acquiring new skills to live independently and she likes that she can go on her own, take the bus and go to do the shopping. Similarly, she likes that she is able to manage her money without help, as she used to be scared of the process. She said that she would like to move again because she would prefer to live in another town where she is not well known. She would recommend to people to move to independent living as she 'got on very well'. Her key worker said that she is very independent as she only requires five to ten hours support per week, but her key worker said she can observe that she is now upset because she (Patricia) realised that her life could have been different if living independently earlier.

### Tom

Tom is an Irish male of 54 years of age with ID. At the time of the interview (November 22<sup>nd</sup> 2012), he was living independently whereas previously he lived in a community house. Tom reported that since the move to the personalised settings he had more opportunities to do exercise and to cook healthy food. He is engaged in the community, being part of the 'residents association' in his neighbourhood. At the time of the interview, he was engaged in voluntary work in a local charity shop and he expressed his desire to have paid employment. His key worker stated that Tom had some health problems, namely glaucoma and high blood pressure. Tom's key

worker worked before in an institution, so he makes account of the differences between the services and the environment in each setting (congregated and personalised).

### Lucy

Lucy is an Irish female, 53 years of age, and is single. Lucy was living in an institution for people with disabilities for 40 years, sharing facilities with over 22 persons with intellectual disability. Lucy previously moved to a personalised setting, sharing a house with a younger female. The first move had different aspects that can be attributed to the first move not being successful which Lucy and her key worker describe. In the first instance, the people responsible for her move to the community did not give her enough notice. Her move out of the institution was announced to Lucy only one day previous to the move, when her key worker was away on holidays, unable to provide support and assurance to ease the transition. Another reason was incompatibility between Lucy and the other housemate; there was an age gap and they had very little in common. Lucy was engaged in part time paid employment and voluntary work at T1 interview, while at T3, she was only engaged in voluntary work. Her key worker was interviewed.

### Jack

Jack is an Irish male of 57 years of age with MHP. He was living independently at the time of the interview (February 28<sup>th</sup> 2013). He moved to a personalised setting on May 2012, an apartment that he chose from different options that were given to him. He previously resided (from 1 to 4 years) in a cluster of houses for people with mental health problems where he shared a house with at least seven more individuals with disabilities. Jack was engaged in voluntary work at T1, however this changed at T3.

Jack outlined the support that he had received in moving to the personalised setting. He said that it was the right time and he had great staff supporting him. He previously was given the opportunity to move from the congregated setting but he got a bad reaction towards it because he did not have any notice and nobody had asked him if he wanted to do it or to make sure he was prepared for the move.

## **Appendix X - Background information for Congregated setting Case Study**

### Janet

Janet, a 61 year old Irish female with intellectual disability who at the time of the interview (04 March 2013) was single and living in a congregated setting. Janet had lived in the institution for over 10 years; sharing the facilities with at least 10 more disabled people. During the interview she constantly expressed her dislike for the institution and her aspirations to move to a house. In answer to the majority of the questions, she insisted on wanting her new house and wanted to being brought to it, to take a look at it, she asked if it was ready for her. She did not provide further information. Both, a relative (her father) and her key worker provided supplementary information about Janet's experiences and their own perspectives of her life in the congregated setting.

### Paul

Paul, a 62 year old Irish male, divorced with MHP. He went to ordinary school and completed higher education. At the time of the interview (January 16<sup>th</sup> 2013) he was living in a community hospital for people with mental illness for over five years; sharing facilities with at least 18 other people with MHP. Although he moved to an apartment on his own recently for a couple of months, he went back to the community hospital; some of the reasons were discussed by his relative and key worker. He expressed his aspirations to move to the community again with certain reservations related to self-medication as he reported to need assistance and supervision in the area.

### Maureen

Maureen is an Irish female 38 years of age. She lived in a congregated setting for people with ID for over 10 years, where she shared the facilities with over 29 other females with ID, sharing a room with at least 4 more persons with ID. She was not working at T1 or T3, she was not engaged in voluntary work at T1, but she was engaged in voluntary work at T3. Maureen was not interviewed, but information was collected from a relative and her key worker.

Maureen at the time of the interview (January 8<sup>th</sup> 2013) had moved from the congregated setting to a group home. However, it was decided by the researcher to include her story in the congregated settings case study as, based on the literature, many authors considered group homes as a replica of congregated settings practices only on a “smaller scale”, where disabled people do not have a choice of where to live and who are the support staff.

## **Appendix XI - Background information for Family Home Case Study**

### Lisa

A 20 year old Irish female with intellectual disability who at the time of the interview (February, 2013) was single and living in the family home with both of her parents and an older brother. Her key worker describes the space Lisa's has within the family home: "she has her own side of the house and the built extension, so that's Lisa's side [of the house]. She has her own bathroom and sitting room down stairs and upstairs she has her own bedroom, so it is a very good set up for her". Thus, Lisa has her own space, however, she did not have a front gate or door to the house and as she acknowledged it, she had to access her place "going in through the house".

### Robert

Robert is a 24 year old Irish male with intellectual disability who at the time of the interview (February, 2013) was single and living in the family home with mother and father.