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An exploratory study of the impact of a proposed move to dispersed housing on the perceptions and attitudes of family members of people with intellectual disabilities.

Roisin Nic Ginneá

K00118425

Supervised by: Dr Matthew Cannon

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Declaration

The work presented in this dissertation is the original work of the author, under the direction of Dr Matthew Cannon and due reference has been made, where necessary, to the work of others. No part of this dissertation has been previously submitted to LIT or any other Institute.

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Masters Candidate **Date**

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Main Supervisor **Date:**

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Second supervisor (if applicable) **Date**

Abstract

The "Time to Move on from Congregated Settings" report (HSE, 2011) has sparked much debate among families of those who face the proposed move to dispersed housing in the community. A congregated setting is defined as a place where ten or more people with disabilities live; the strategy's main objective is to transition all residents from congregated settings to community living arrangements.

The overall research aim was to enhance understanding by engaging with the family members on the impact of a proposed move to dispersed housing on their perceptions and attitudes. The research involved a detailed review of the existing literature and a number of gaps were identified. The study explored the opinions of the family members in relation to what type of living arrangement they think is most suitable for their family member. To achieve the overall aim of the study the following objectives were formulated; to identify if the level of disability or impairment have an impact on the suitability of living arrangements; to evaluate the perspectives of the families on dispersed housing in the community and to determine the main considerations and expectations that family members have for their relative in relation to living arrangements.

A qualitative study design was employed which entailed semi- structured interviews. A combination of sampling techniques, both convenience and purposive were used which enabled the researcher to select participants who were informed in relation to decongregation and also representatives of residents and their needs and wishes.

The findings of the study are presented under the themes and subthemes which emerged as part of the data analysis and coding process. The main themes included quality of existing supports in the campus-based setting, impact of the level of disability or impairment on suitability of living arrangements, perceived lack of supports in the community and perceived lack of safety or opportunities for independence in the community. Some of these findings reflected aspects of the literature review however; more findings directly contradicted existing research.

It was concluded that families were happy with their relatives' current campus-based setting and were opposed to proposed moves to dispersed housing in the community. However, families acknowledged that they were not opposed to the 'Time to move on from Congregated Settings' strategy but that the strategy should only be implemented for those who choose to live in the community and that it should allow choice for those who choose to stay in their current 'congregated setting'.

Recommendations include the need for further research to explore the views of residents and their families in relation to the most appropriate living arrangement for them. It is recommended that policy makers should facilitate consultation with families. The researcher also recommends that the Health Service Executive (HSE) need to access current congregated settings and recognise good quality

settings which could be improved. Finally, that the HSE should prioritise creating residential placements and support for people with intellectual disabilities who are residing at home or inappropriately placed in nursing homes.

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CONTENTS

Chapter 1: INTRODUCTION

1.1 Introduction

This study explores the impact of a proposed move to dispersed housing on the perceptions and attitudes of family members of people with intellectual disabilities. This chapter introduces the aims of the study as well as the context and rationale for the research. This chapter will also provide an outline of the study.

1.2 Aims & Objectives of the study

The overall research aim is to enhance understanding by engaging with the family members on the impact of a proposed move to dispersed housing on their perceptions and attitudes. The study will explore the opinions of the family members in relation to what type of living arrangement they think is most suitable for their family member. To achieve the overall aim of the study the following objectives have been formulated:

- Explore the perceptions and attitudes of the families on the "Time to Move on from Congregated Settings" Report.
- Identify if the level of disability or impairment have an impact on the suitability of living arrangements.
- Evaluate the perspectives of the families on dispersed housing in the community.
- Determine the main considerations and expectations that family members have for their relative in relation to living arrangements.

These objectives will be addressed qualitatively by exploring them with seven family members of people with intellectual disabilities residing in a campus-based setting through the use of semi-structured interviews. These objectives will be explored ethically with all ethical considerations underpinning the research method.

1.3 Background context and research rationale

A strategy designed by the Health Executive Service (HSE) to implement deinstitutionalisation in Ireland: "Time to Move on from Congregated Settings- A strategy for community inclusion" (HSE, 2011) has derived a policy which intends to move out 4,000 people living across 72 congregated settings to 'community-based' living arrangements. 'Congregated settings' are defined as "ten or more people sharing a single living unit or where the living arrangements are campus-based" (HSE, 2011).

This report was developed by a working group whose aim and commitment has been to make a compelling case to change the practice of congregated settings. The report suggests that the objective of decongregation is to create a new model of support in the community, in which residents avail of housing provided by local authorities and that residents access the same healthcare and social services as the general population. This report describes the policy implementation as a developmental tool to improve community inclusion for people with intellectual disabilities.

The report outlines how there may be resistance from many, including family members of affected residents. However, this is not explored in depth and specific concerns are not discussed within the report.

Ironically, in 2016 it became apparent in a number of media reports that family members had resisted against their family members being moved out of campus-based settings in two different locations in Ireland. In one location through a resistance campaign, the immediate threat of closure of the congregated setting was halted and families continue to fight against the decongregation of their relatives.

Although there is a wide variety of literature on deinstitutionalisation and post-deinstitutionalisation there is a gap in research in relation to the perspectives of residents. It is important to acknowledge that due to ethical considerations and potential communication difficulties that there are significant limitations to carrying out this type of research.

However, this research aimed to gain insight into the perceptions and attitudes of those who know the residents best, the family members. It could be assumed that the family members would have a better understanding of the most appropriate living arrangement for their relative.

Existing literature presents a significant challenge on whether congregated settings or dispersed housing in the community provides better outcomes for people with intellectual disabilities. A significant number of studies focused on quality of life as a measure of how successful moving from congregated settings to the community had been for some.

The concept of Quality of Life is being increasingly used to plan, deliver and evaluate services for people with intellectual disabilities which evolved from “normalisation” and “inclusion” movements (Felce, 1997). However, it could be suggested that the reliability of these studies is compromised as there is a lack of systematic design across studies. This includes the variations in what was measured and the type of settings considered in the research. Much of the research was carried out on larger scale settings such as psychiatric hospitals which found increased isolation and segregation of residents. However, there is little research in relation to more modern, smaller scale congregated settings which creates difficulties as there is little comparable research.

Studies which examined the outcomes for those who had moved from congregated settings to dispersed housing in the community fail to present evidence that residents experienced increased community inclusion. Although some studies found greater social networks in the community the studies failed to find that this resulted in greater community integration for residents (Beadle-Brown et al, 2007; Forrester- Jones et al, 2006; Stancliffe and Lakin, 2006). Hall

& Hewson (2006) carried out a study which found no increase in community links for residents who had moved from congregated settings to dispersed housing in the community.

It is widely acknowledged that there are many challenges for people to live successfully in the community. It has been found that the severity of a person's intellectual disability has an impact on the quality of life experienced within the community (Abbot & Mc Conkey, 2006; Smith et al, 2005). Many authors have found that a move to the community for some has only been associated with modest gain in certain areas of their quality of life (Cox and Pearson, 1995; Grover, 1995; Jackson, 1996; Segal, 1990).

Some authors suggest that policy makers should focus on creating a sense of community connectedness rather than physically placing people in the community. Proponents suggest that campus-based settings which have been set up as intentional communities can provide more opportunities than community living (Cox & Pearson, 1995 and Cummins & Lau, 2003, Chowdhury and Benson, 2011).

The aim of the study is to learn from the lived experience of the relatives who have been faced with proposed moves to the community. The researcher feels that the family's perceptions and attitudes towards dispersed housing in the community is invaluable as they provide an insight into how a move would affect those central to the move, the residents.

1.4 Outline of the study

Chapter 1 introduces the aims of the study and explains the context and rationale for the research.

Chapter 2 summaries a review of research literature on deinstitutionalisation and post-deinstitutionalisation. The literature review is presenting under themes including, types of residential settings, quality of life, difficulties in comparable research, outcomes of community living, challenges of community integration, level of impairment, creating intentional communities and future planning.

Chapter 3 describes and critically discusses the methodology used to carry out the research. It outlines the rationale for and the explanation of the method selected and details of the process of data collection, interpretation and analysis. The limitations of study and the ethical considerations are also identified and discussed.

Chapter 4 presents a summary of the main findings emerged from six qualitative interviews. The findings of the study are presented under the themes and subthemes which emerged as part of the data analysis and coding process.

Chapter 5 discussed the research findings outlined in chapter 4 in the context of the literature review and gives due regard to the aims and objectives of the study. It also provides an in-depth analysis of the main themes presented in chapter 4. Implications of the findings are then considered.

Chapter 6 concludes the research by seeking to specifically answer the research questions and suggest possible avenues for further study.

Conclusion

Although there has been significant research carried out in relation to deinstitutionalised it could be suggested that there are a number of gaps within the available research. The lack of research in relation to the impact on the residents and their relatives has provided the researcher with the opportunity to gain insight which can contribute to a wider understanding of decongregation.

Chapter 2: LITERATURE REVIEW

2.1 Introduction

The aim of this research is to address the attitudes of family members of people currently living in campus-based settings and their attitudes on the plan to move those people to dispersed housing in the community.

The “Time to Move on from Congregated Settings” report was published by the Health Service Executive in 2011 (HSE, 2011). This report was devised as a strategy for community inclusion. In this report the HSE (2011) focuses on moving people from “congregated settings” to the community. This report defines congregated settings as a place where ten or more people with intellectual disabilities live together. Inclusion Ireland (2015) state that over 4,000 people with intellectual disabilities live in congregated settings.

There is a wide variety of literature on deinstitutionalisation and post deinstitutionalisation internationally (Bigby, 2008; Chowdhury &Benson, 2011; Mansell, 2006; Mansell & Beadle-Brown, 2009; Kozma et al, 2009; Segal, 1990; Stancliffe et al, 2005) and research has also been conducted in Ireland (Emerson &Hatton, 1996; Fleming, 1997; McConkey, 2007). Studies on deinstitutionalisation primarily aim to evaluate the impact of the process of deinstitutionalisation on the quality of life of people with intellectual disabilities. In contrast, post- deinstitutionalisation studies aim to either compare quality of life outcomes across different types of ‘community based’ residences or to identify factors associated within ‘community based’ residences.

A growing number of authors have different conceptualization of residential settings and definitions vary which is a hindrance in comparing quality of life outcomes results across different settings. Some researchers categorize larger settings exclusively by size and others similarly to the “Time to Move on from Congregated Settings” report by the number of residents living in the same house or location (HSE, 2011).

The literature review is presented under thematic headings and outlines current institutional context. It also identifies the need for change and the nature of the proposed changes is also addressed. There are huge gaps in the literature in relation to the perspectives of the families of those who are facing the proposed moves to dispersed housing in the community due to the policy of decongregation.

2.2 Types of residential settings

There are a number of different residential settings referred to as institutional settings across international literature. Even nationally there are difficulties when comparing research as older literature does not refer to congregated settings as it is a relatively new concept that was established with the “Time to Move on From Congregated Settings” report (HSE, 2011).

The difficulties to having a defined and agreed categorisation of institutions or congregated settings is also affected by the differences in national policies and the types of services that are provided in different countries at different stages of history (Felce & Emerson, 2001).

However, it is possible to identify common settings that are identified by authors as institutions:

(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 not defined merely by size" (European Coalition for Community Living, 2013). Mansell & Beadle- Brown (2010) state that these types of settings are usually visually different and the architecture of the buildings are usually different to the rest of the buildings in the community and that typically a number of residents share units or bedrooms.

(b) Clustered housing/ campus-based settings refer to village style communities and residential campuses. Mansell (2006) suggests that these were smaller institutions that were formed for earlier deinstitutionalisation. Mansell & Beadle Brown (2009) suggest that these settings can be characterised due to a number of living units forming a separate community from the surrounding population. These can be considered as congregated settings because although less people are sharing the facilities, they still share institutional like features.

(c) Group homes, are considered as apartments or houses of the same types, located among ordinary houses and are usually occupied by six residents (Mansell & Beadle-Brown 2009 and McConkey, 2009).

2.3 Quality of Life

The concept of Quality of Life has been developed over many decades and applied to a wide range of target groups and whole populations. It is increasingly being used to plan, deliver and evaluate services for people with intellectual disabilities. Felce (1997) suggests that it has evolved from the 'normalisation' and 'inclusion' movements and its influences can be seen in legislation, policies and programmes that aim to improve the lives, personal satisfaction, success, community membership and participation of individuals with disabilities (Silvana et al. 2002).

The concept of Quality of Life has been used by many authors in an effort to measure how different residential settings impact on the lives of residents (Jansen et al, 2006; Melville et al, 2006; Mc Conkey et al, 2007; Young et al, 2001).

2.4 Difficulties in comparable research

Existing research demonstrates that individuals with intellectual and developmental disabilities living in the community experience a greater quality of life compared with individuals living in segregated institutional settings (Jansen et al, 2006; Melville et al, 2006; Mc Conkey et al, 2007; Young et al, 2001). However this is not a clear cut disagreement as there are many aspects to this deinstitutionalisation.

A large body of post- deinstitutionalisation evidence does support the hypothesis that moving from an institutional residential setting to a community residential setting is associated with an improved quality of life for adults with intellectual disabilities settings (Emerson & Hatton, 1996; Jansen et al, 2006; Melville et al, 2006; Young et al, 2001). However, it must be considered that these are based on small samples and that a lack of systematic design and variations in what was measured, some in older institutions means that majority of the study's results could be considered as unreliable data in relation to the experiences of those who have moved to 'community based' settings. This challenges the validity of the results.

Some researcher's categorised larger settings exclusively by size as institutions while others considered clustered homes and residential campuses as institutions. References to "congregated settings" were scarce in the international literature and the samples used in most studies focused on bigger institutions and not smaller congregated or campus-based settings.

Lutz (2017) argues that studies fail to support a case against intentional communities. It is hardly surprising in the past that researchers have found isolation and segregation among residents who lived in larger scale settings with a lack of access to the greater community. While no one is advocating returning to hospital, institutional based care settings model, it could be suggested that we could simply improve by focusing on improving our current settings, best practice and community inclusion and focus less on physically moving residents to the community to promote community inclusion and improved quality of life.

A small percentage of existing literature supports this theory. Emerson et al (2000) suggests that campus-based/ cluster housing offers different though not inferior quality of life in comparison to dispersed housing.

A gap that the author has identified in the existing literature is to explore the perhaps positive aspects of living in campus-based settings and the attitudes of family members towards the strategy to move people with intellectual disabilities to the community.

2.5 Outcomes of community living

Although existing research has suggested that moving people from institutions to 'community based' settings is a positive step, this is contested by some authors. It is suggested that moving people with intellectual disabilities to the community does not necessarily lead to increases in levels of social contacts or community inclusion (Beadle-Brown et al, 2007; Hall &Hewson, 2006; Forrester-Jones et al, 2006; Young, 2006).

Hall & Hewson (2006) found no change in community links over a 7 year period in 'community based' settings after moving from a hospital. Hall & Hewson

(2006) determined that 88% of those included in research accessed the community less than once a day.

Findings of various studies show that the process of deinstitutionalisation helped people to have a greater social network but that living in a 'community based' setting did not result in people integrating into the community (Beadle-Brown et al, 2007; Forrester-Jones et al, 2006; Stancliffe and Lakin, 2006).

The quality of these social networks were further examined and a study of over 200 participates examined their social networks after being moving to the community and 68% of the social networks were made up of people related to the service both in the form of staff and peer contact (Forrester-Jones et al, 2006).

A wide variety of the research that has been conducted has raised questions about the level of integration that is possible for people with intellectual disabilities within communities and that there are many challenges for people to live in the community successfully.

2.6 Challenges of community integration

Several studies have found that severity of a person's intellectual disability also plays a huge role in the difference of the quality of life experienced by people within the community (Abbot and McConkey, 2006; Smith et al, 2005). Findings suggest that those whose intellectual disabilities were considered severe experienced less social inclusion, didn't participate in the same levels of meaningful activities and experienced less choice (Abbot and McConkey, 2006).

This is especially true for people with more complex needs such as challenging behaviour. It is widely acknowledged that some people with intellectual disabilities with high support needs and challenging behaviour can be supported successfully in the community; however improvements are not experienced by all (Mansell and Beadle- Brown, 2009).

Hall & Hewson (2006) argue that moving people from larger institutions to alternative grouped living arrangements is creating mini-institutions which replicate many of the features of the old but simply in a building which is based in a housing estate or on a street. It could also be suggested that the same issues and barriers to social inclusion are still prevalent even when living in the community.

Emerson (2004) suggests that in general the move from institutions to the community has been associated with a range of positive outcomes for people with intellectual disabilities. However, many commentators have argued that deinstitutionalisation has only been associated with modest gains in certain areas which are considered to be central to the quality of life of people with intellectual disabilities (Cox and Pearson, 1995; Grover, 1995; Jackson, 1996; Segal, 1990).

This supports the theory that levels of impairment and severity of intellectual disability affect the outcomes of people who move to the community. Baker (2007) found that people who had severe intellectual disabilities had limited interaction possibilities in the community and had no change whether living in a campus-based setting or in the community. This would suggest that there has to be some discussion around the suitability of community living for some people with intellectual disabilities, particularly those whose disability is considered severe or profound. Existing literature suggests that intentional communities or campus-based settings may provide better outcomes for some people.

Perhaps this is why there has been resistance from families to move their relatives from campus-based settings to the community. One could argue that campus-based settings can provide increased safety and independence for people with severe or profound disabilities e.g. drive go karts, go swimming, opportunities that may not be available to them if they were to live in dispersed housing in the community.

2.7 Level of Impairment

Level of impairment and severity of disability also impacts findings; obviously where those people whose intellectual disability is perhaps mild and their impairment slight their community participation and outcomes will be greater because they have the capacity to access more services. Kozma et al (2009) found that the people with the least impairment had the most positive outcomes following a move to dispersed housing. The “Time to Move on From Congregated Settings” report (HSE, 2011) does not take this into account and it is a one size fits all approach. It could be suggested that this one size fits all approach creates a situation whether person- centred practice is ignored and the drive to move away from congregated settings becomes a priority for policy makers and service providers.

Evidently, in 2018 the media reported that a whistle-blower from a service provider who supports people with intellectual disabilities alleged that “serious wrongdoing” had been taken place in the service. The whistle-blower claimed that a group of individuals at the organisation had conspired to falsify official documents for the purpose of portraying a resident as more independent and suitable for community living as to underestimate the level of support that was needed to live successfully in the community (MacNamee, 2018).

It could be suggested that the issues around decongregation are not solely based on the types of appropriate settings or what settings provide the best outcomes for residents. But that the services do not have the resources to fund appropriate support whether residents reside on campus or in the community. It could be suggested that the issues arise due to poor service provision and lack of funding to adequately support residents, regardless of their living arrangements.

2.8 Creating intentional communities

The Time to Move on from Congregated Settings (HSE, 2011) report highlights that it aims to give people with intellectual disabilities choice. However, it is not considered in this report that the deinstitutionalisation strategy may be taking the right of individual to choose where they live, albeit if they wish to live in “institutions”.

Chowdhury and Benson (2011) argue that services should focus on a "sense of community connectedness" rather than focusing on physically placing people in the community. This supports the view of Lutz (2017) that it's not necessarily to physical environment of where people live but it's the restrictive practices of larger institutions that impact negatively on resident's lives.

Literature is limited in the area of the potential distress that people with intellectual disabilities may experience if moved from a familiar setting with people with whom they may have lived with for a long time and with caregivers they know well to a new 'community based' setting of which they are not familiar with. The literature also fails to recognise the potential resistance of individuals or their families to moving from congregated settings.

Mansell and Beadle- Brown (2009) cite that there is extensive evidence in the literature on the overall benefits of deinstitutionalisation and it has been contested by many researchers that cluster housing in the community or campus-based settings are more effective.

Some argue that deinstitutionalisation has been a failure and suggest that cluster or campus-based living arrangements are more beneficial to people with intellectual disabilities. Proponents suggest that cluster or campus-based settings which are set up as intentional communities of people with intellectual disabilities provide the opportunity for people to integrate with other people of similar interests (Cox & Pearson, 1995 and Cummins & Lau, 2003, Chowdhury and Benson, 2011).

Cummins & Lau (2003) state that they found no evidence to suggest that cluster or campus-based settings cause harm to those that live in them. It has also been suggested that policy is developed to benefit the individual but that it has a narrow focus on social integration of which people with intellectual disabilities find difficult to achieve.

This focus of social integration can be more stressful than beneficial to individuals. Many authors argue that service provision should focus on achieving a sense of connectedness rather than the physical integration and this could be achieved within a community of people with intellectual disabilities living in close proximity (Cummins & Lau, 2003 and Chowdhury & Benson, 2011).

In contrast, Emerson (2004) found that of the people living in campus-based or cluster living arrangements were more likely to live in larger settings, be supported by fewer staff members, experience change more frequently and experienced more restrictive practices. Emerson (2004) suggests that there were few benefits of living in cluster housing and found that this living arrangement offered a poorer quality of life and care than dispersed housing schemes. Emerson (2004: p.195) also argued that there was no evidence to suggest that cluster living arrangements "…provided a connected community of people with intellectual disabilities". Emerson's research (1996; 2000; 2004) continues to contradict findings that suggest that campus-based settings provide greater outcomes.

Although extensive research has provided compelling evidence that dispersed living arrangements in the community are of great benefit to residents (Emerson, 2004; Melville et al, 2006 and Young et al, 2001). It could be suggested that providing accommodation for in excess of 4,000 people (who currently live in congregated settings) cannot be limited to a narrow, one size fits all approach and that a variety of living arrangements would benefit a variety of people who have different likes, dislikes, abilities and needs.

The compelling evidence to suggest that campus-based settings provide positive outcomes for people with intellectual disabilities, these findings are based on varied research methods (Cummins & Lau, 2003 and Chowdhury & Benson, 2011, McConkey, 2007). The validity of both the opposition's findings must be questioned as authors are not only finding mere discrepancies in findings but totally conflicting outcomes.

McConkey (2007) found that those in clustered settings actually had greater levels of social inclusion as measured by their use of community amenities and social contacts than did those in small group homes. Similarly, in Horwitz et al (2000) found that village communities for adults that are physically segregated from the local community offer "a distinct pattern of benefits" as opposed to dispersed models, including greater opportunities for choice making and satisfaction.

From the review of existing literature it would suggest that cluster like arrangements or campus-based settings report to have the best outcomes for people with disabilities.

This research aims to explore the attitudes of family members of those affected by this strategy of moving from congregated settings. Ideally this research would focus on the attitudes of the residents, however due to communication and comprehension difficulties affecting some individuals this study focuses on the attitudes of those who know them best; their family members. This study hopes to understand the resistance of change from families and the reasons that the families believe that not moving to the community is in the best interest of their relatives.

The main objective of this research is to gain meaningful insight into the lives of people living in campus-based settings and their experiences of their current living arrangements and attitudes of the plan to move them to dispersed housing in the community from the perspectives of their family members. This research will take a qualitative approach using semi-structured interviews will be used to allow participants to share their feeling, belief and attitudes (Moore, 2000).

Doody (2011) explored the views of family members of people with intellectual disabilities that had moved from a long stay psychiatric institution to a campus-based setting. The overall findings suggest that families were happy with the move and felt it benefited the individual. Doody (2011) states that families made reference to concerns of splitting peers and that there were like "family". The campus-based setting provided suitable accommodation which family members suggested bred a new culture of nursing staff who improved the involvement of residents and families in the care of individuals (Doody, 2011).

However, this is not entirely valid as this research project is focused on the type of modern age deinstitutionalisation, which is no longer focused on moving from State run long stay psychiatric hospitals but from settings where ten or more people with intellectual disabilities reside together. It would be easy to anticipate that families would be happier with a move from a psychiatric hospital and that there would not be the same level of resistance but what about settings that the families are happy with?

Interestingly, in 2016 some families of residents in Áras Attracta vocalised their concerns about potential plans to move their family members to the community, this was subsequent to the RTÉ coverage of allegations of abuse at the facility (Ryan, 2016). Similarly in 2016, a group of concerned family members of people living in a campus-based setting in Kerry lobbied to the local county council for their support to stop the plan to move residents to the community (RTÉ News Now, 2016).

Although these families have voiced their concerns to government and media- no research in Ireland has specifically examined the concerns of the families of those directly affected by the National Strategy of decongregation in Ireland in 2019.

Bigby (2008) cites that in Australia and New Zealand there has been a change in the policy of deinstitutionalisation and that more cluster housing arrangements have been developed and people who were moved out to the community to dispersed housing from institutions have been moved back to these. In particular, people with challenging behaviour were more likely to be re-institutionalised after moving to the community (Beadle et al, 2007 and Bhaunik et al 2009).

It could be suggested that Ireland is at risk of making the same mistakes. Moving away from campus-based settings to dispersed housing in the community to find out that the perceived positive outcomes are not achievable and that the previous campus-based settings were more beneficial for residents. The “Time to Move on from Congregated Settings” report seems to lack any allowances or take into account the need for future planning. In particular the need for future planning for the changing needs among the aging population of people with intellectual disabilities.

2.9 Future Planning

Very few commentators make reference to future planning within their suggestions about the best living arrangements for people with disabilities. People with intellectual disabilities have an increased life expectancy and while this is very positive it does create a strain on service provision. Most people who live at home with their families will need a residential placement as their carer’s age beyond a caring capacity and it is inevitable that additional residential provision will be required (Kelly et al, 2010).

The overall trend of people with intellectual disabilities availing of full- time residential placements has decreased in recent years. However, the cause of this is not clear. It could be suggested that it is a lack of provision and not a choice made by families or the people with intellectual disabilities.

There appears to be very little planning around how the changing needs of the aging population of people with intellectual disabilities will be met. Kelly et al (2010) states that the National Intellectual Disability Database cites that many people with intellectual disabilities are moving to institutional settings as they age.

In the general population people develop dementia and have unique and complex needs, and for many family caregivers, despite their best efforts to provide home care to relatives with dementia for as long as possible, a time will come when decisions need to be made about long-term residential care. However, this is especially true among those with intellectual disabilities and particular those people who have Down syndrome.

Irish Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) has carried out research over a 20 year period with people with Down syndrome in Ireland and found very high prevalence rates, significantly earlier onset than in the general population and high risk rates for dementia for people with Down syndrome (McCarron et al, 2011).

The key findings 97.4% of the participants assessed developed dementia over the 20 year period. In the general population, the estimated prevalence rates are 5-7% in people aged 65 years and over. The study also found that 80% of people with Down syndrome and dementia will develop new onset epilepsy, in contrast to 11% in the general population.

This new data has major implications from a care and resource perspective. It could be suggested that dispersed community living arrangements are the least appropriate living arrangement for people who have dementia and that specialised intentional communities are more practical. This should be considered in the National policy. There is no evidence that it has been taken into account in the “Time to Move on From Congregated Settings” report (HSE, 2011).

In the general population this need of the aging population has been identified and specialised dementia care settings have been developed and now provide clustered style residential service provision. However, it appears that this has not been taken into consideration for people with intellectual disabilities.

2.10 Conclusion

A number of gaps in the existing literature have been identified which this research project aims to explore. The biggest gap in existing research is the lack of perspective of the views of families of those at the centre of the plans to move to dispersed housing. This research project is particularly interested in the views of participants who are happy with their current residences and do not see a move to the community as a positive one.

The resistance of some families to agree for their relatives to be moved is also an area that remains unclear and their reasons for this resistance are unclear. This research will aim to uncover the attitudes of the families towards the “Time to

Move on From Congregated Settings" (HSE, 2011) strategy and plans to close existing congregated settings.

There is no evidence to suggest that any of the literature has explored what the impact of decongregation has on residents who have moved to the community from their life-long residences and any potential distress they may have suffered due to the move.

This research project aims to explore a wider perspective of the attitudes towards the "Time to Move on From Congregated Settings" (HSE, 2011) strategy with those who are directly affected by it.

Chapter 3: METHODOLOGY

3.1 Introduction

This chapter presents the methodology and research method used in this research. The chapter outlines the rationale for and explanation of the method selected and details of the process of data collection, interpretation and analysis. Furthermore, the limitations of the study are identified and discussed. Finally, the chapter identifies and discusses the ethical issues that were taken into consideration and underpinned the design and implementation of the study.

3.2 Research Rationale

This research project involved a detailed review of existing literature in relation to deinstitutionalisation in Ireland and internationally. A gap was identified and the perspectives of the people at the centre of this policy were not being represented in the literature. The optimum method to explore the perspectives of this group would be to interview them directly.

However, due to ethical considerations and communication difficulties the researcher opted to conduct the research with family members of residents as it would provide an insight into this gap in information. Ultimately, the overall aim of the study is to enhance understanding through engaging with the people who know residents best- the families, making them worthwhile research participants.

3.3 Research Theoretical Approach

Given that a gap in research was identified, the best research approach was considered. According to Blanche et al (2007) the development of the research design has to be based on whether the study is exploratory, explanatory or descriptive. As the study was exploratory in nature it therefore fits with an approach emphasising the generation of theories, rather than testing current theories as is inherent in quantitative research (Holloway, 2005).

To gain a valuable insight and understanding into the perspectives of family members a qualitative research approach was chosen. Qualitative data can give a richness and depth that is unlikely to be obtained through other methods, as it involves personal contact and insight and places the findings in a social, historical and policy context.

Qualitative research was chosen as the exploratory research method for this project and comes from an interpretative perspective and is concerned with interpreting and understanding phenomena through the meaning that people attach to them (Greenhalgh, 2001). Qualitative research is the use of techniques of data collection and analysis that processes word based and non-statistical data (Holloway, 2005; Blanche et al, 2007).

Creswell (2011) suggests that understanding "lived experience" marks "phenomenology" as both a philosophy and as a method of research. Phenomenology believes knowledge and understanding are embedded in our everyday world and it cannot be quantified or reduced to numbers or statistics.

Bryman has referred to it as 'seeing through the eyes of the people you are studying' (Bryman1988: 61). Therefore, this study adopts a "phenomenological" research strategy and design together with a "qualitative" research approach.

3.4 Sampling

A combination of sampling techniques was used for this study. Convenience sampling was used as the researcher selected a local parents committee, to which some personal affiliation existed prior to the study. The other technique used to select the research participants was purposive sampling. Purposive sampling is defined as non-probability sampling technique where the participants selected are the "most informative or representative..." of the population (Babbie, 2007: p.204). This is widely used in qualitative research as it selects the most information rich sources. Holloway (2005) suggests that it is essential to identify the most knowledgeable members of the population to collect the data and is considered the most effective way for selection of participants for the research.

The sample size of six is considered to be sufficient to reach saturation of information in qualitative research. Guest, Bunce & Johnson (2006) noted that data saturation in rich qualitative studies can be attained from a sample size as small as six interviews; two participants took part in a joint interview.

The chosen sample for this research was determined initially by a gate keeper. The researcher contacted a family committee of a campus-based setting. The gate keeper shared the researchers' contact details with the families and interested participants contacted the researcher directly. The sample was chosen specifically on location and availability to meet.

The response from families was quite high with over ten people sharing their contact details with the researcher. A gender balance was difficult to maintain with most respondents being female. Six females and one male were chosen to participate in the research.

3.5 Data collection methods

Moore (2006) suggests that approaches to collecting qualitative data are much less structured and formal than techniques used to gather quantitative data. Qualitative data collection methods can vary from interviews, focus groups and surveys. Holloway (2005) suggests that interviews are the most utilized data collection method of qualitative research. For the purpose of this research project the chosen method was semi-structured interviews.

Gallette (2012) suggests that semi-structured interviews have the potential to add complexity to information that may need contextualisation. Semi-structured interviews use a variation of questions and prompts which can increase the in depth knowledge while still looking for the participants spontaneous views.

Mason (2002) states that research interviews must have some sort of structure to be effective in gaining insight; a single opening question can prompt the thought and discussion between researcher and participant. A semi-structured interview provides an opportunity for the participant to have some control within the interview and to draw on aspects of experience that are important to them (Holloway, 2005).

The researcher chose to carry out semi-structured interviews as it would allow for a more in depth analysis of the research question and that they may give an opportunity to gain insight into new themes of information that has not been portrayed in existing literature. The six interviews, one of which was a joint interview, were audio recorded and then transcribed verbatim (see appendix D for full transcripts). The interviews were carried out at locations convenient to the participants and the setting was chosen by participants.

Interviewees were informed of the purpose of this research and all ethical guidelines were adhered to throughout the interview process. The researcher provided interviewees with information letters (see Appendix B) stating the purpose of the research and contact details of the researcher. The researcher sought informed consent by providing detailed information on how the data would be collected, stored securely and presented and what measures would be used to ensure confidentiality and anonymity of participants (see Appendix C).

3.6 Data analysis

Moore (2006) suggests that there is a presumption that analysing qualitative data is easier than quantitative data but this is incorrect. Analysing qualitative data is difficult and requires the researcher to have a perspective approach to the data. However, the quality of the data can be much more informative and useful than quantitative data if carried out successfully (Moore, 2006).

Analysis should be done throughout the research process and not left until the end of data collection (Tesch, 1990; Moore, 2006). The researcher identified themes from the first interview conducted and used this data to inform the next interview. The collection and analysis of data were integrated throughout the process.

The researcher conducted the interviews with an open mind and was conscious not to only look for information that confirmed to early interpretations, not only that but the researcher looked for information that undermined the early interpretations (Moore, 2006).

The researcher listened to, transcribed and read the transcripts to identify significant themes throughout the interviews. Moore (2006) suggests that this is what qualitative research requires- total immersion of the researcher into the data to gain a deeper understanding of what is going on for respondents.

The data from the transcripts was collated by the researcher and thematically analysed. The thematic analysis is presented in chapter four and further discussed in chapter five, in line with the literature review.

3.7 Researcher Reflexivity:

Malterud (2001) suggest that a researcher's experience and background will affect what they choose to investigate, the angle of the investigation and will choose to present the findings they consider to be most appropriate for coming to a conclusion.

The researcher's experience as a family member of a person with an intellectual disability accessing similar services and also the researcher's experience of working in residential settings supporting people with intellectual disabilities may influence the research process.

The researcher used reflective practice after each interview as a means of recognising potential influencing in the questions asked. This was then considered and the researcher identified areas of the interview where potential influencing may have occurred. This mitigated the influence when conducting subsequent interviews and presented the information in a way that preserved the narrative of the participant (Holloway, 2005).

This required the researcher to develop their interviewing skills and decision-making skills. The researcher learned that it was sometimes appropriate to prompt the participant, rephrase questions and make changes based on the interview situation.

This reflective practice also enabled the researcher to identify thematic patterns as they emerged and made the researcher more attentive to similar themes in other interviews and enabled extended exploration of these themes.

3.8 Ethical considerations and confidentiality

The adequate processes have been undertaken to meet ethical responsibilities to protect the participant's rights and to ensure the quality and integrity of this research. This research was carried out within the ethical guidelines for taught postgraduate research dissertations at Limerick Institute of Technology (see Appendix A).

Informed consent was a central component of the research process. Seeking this informed consent required a three step process. Initially, to identify willing participants, contact was made with a gatekeeper who managed the family committee social media outlets. Contact was made with this committee and details of the study were provided which sought willing participants to contact the researcher if they were interested in participating. Respondents were provided with additional information in the context of an explanatory information letter detailing the aims of the research and the role of participants including the amount of time needed to conduct interviews (see appendix B).

When participants were identified for inclusion in this research they were provided with a consent form which detailed in plain language (see appendix C);

- What they are consenting to participate in.
- How to researcher will provide anonymity to participants. This will be achieved by concealing participants names and identifying them by using numbers; participant 1, 2, etc.

- Clarify that participants are free to withdraw from the research at any time without any consequence.
- Details of confidentiality and safe storage of information. This will be achieved by storage of consent forms in a secure document file, which is inaccessible to the public.

Participants were asked to complete these consent forms and return them to the researcher which were then be stored in a secure place.

As the researcher is a former practitioner in the organisation of which participants are involved in, a ‘preamble’ was included with the consent form to ensure that participants felt comfortable and to ensure that no harm would be caused to them. This was also be useful in trying to elicit the honest perspectives of participates. This ‘preamble’ detailed;

- For whom the research is being carried out, this is Limerick Institute of Technology.
- Acknowledge that the research is solely as part of the researchers own studies and is not affiliated with the organisation in any way.
- That the aim of the research is to explore participants’ views, feelings and perspectives, therefore there is no right or wrong answer to the questions asked.
- That questions will be general and open ended to off-set any pressures participants may feel.
- That no direct reference will be made to the organisation that provides the service.
- Acknowledge that participants can withdraw from the research at any time.

To ensure that the research conducted was independent and impartial the researcher reported responses accurately as not to distort the facts. The researcher objectively analysed the data and interpreted the meaning of responses truthfully and also acknowledged the limitations of the research.

3.9 Limitations of the research

There are many limitations for all research approaches and methods. Burnett (2009) suggests that human error has a part to play, particularly in relation to data collection. The researcher strived to transcribe the interviews as verbatim, but there is room for marginal error.

Denscombe (2010) also suggests that data from interviews are based on what people say rather than what they do. The two may not tally and this phenomenon is known as the “interviewer effect‟. Interviews can inhibit participant’s responses and the reliability of interviews could be seen as another disadvantage. It could be suggested that participants may tell the researcher what they think they want to hear, rather than their true thoughts or feelings.

Due to the small sample of this study, it cannot be assumed that the findings are representative of all family members of people with intellectual disabilities residing in campus-based settings across the country. This research is only representative of one setting and may not give a true representation of other settings in the country.

Hyncer (1985) states that reflexivity is important to use when conducting qualitative research. This was particularly important in this study because the researcher is a former staff member in the organisation that is the service provider to these families. This could be a disadvantage and a limitation of the qualitative research unless itis overcome professionally and ethically.

Bryman (2012) suggests that complete objectivity is not feasible and once a researcher does not sway data collection and findings, the researcher can be shown to have acted in a responsible manner. The researcher committed to recording information accurately and did not share their own opinions during the interviews.

Chapter 4: RESULTS

4.1 Introduction

This chapter presents a summary of the main findings that emerged from six qualitative interviews with seven family members of people with intellectual disabilities currently living in a campus-based setting on a proposed move to dispersed housing. The findings of the study are presented under the themes and subthemes which emerged as part of the data analysis and coding process. The key themes that were identified included satisfaction with the existing service impact of the level of disability or impairment on suitability of living arrangement, perceived lack of supports in the community, perceived lack of safety or opportunities for independence in the community, choice, community inclusion, and intentional communities.

4.2 Satisfaction with the quality of existing service

All participants spoke of the quality of existing facilities and specialised services on campus which they fear would not be available in the community. All seven participants spoke of how they were happy with their relatives living arrangements and spoke of how their relatives were happy living in their current campus-based setting. Many spoke about their relatives who were non-verbal and how they judged their happiness on how willing and happy they were when returning to the campus-based setting.

> *"....he has that sense of belonging, there's a huge sense of belonging there like mom says. Like when I was a child he used to come home every weekend now it's every second weekend and he is always home on holidays and stuff as well but mom always says he's always as happy going back in. You know you never see him, there's never any sense of sorrow."*(Participant 6)

All participants interviewed said they did not want their relative to be moved to dispersed housing in the community. One participant stated that she hoped her relative would never be moved from his current campus-based setting and spoke of her fear on how it would impact on his quality of life.

> *"So if you go and move someone from everything they've known then the doors suddenly have to be locked and they can't go out safely on their own I think it's desperately sad. I hope, I hope to God that it never happens to [relative]. I really hope to God it doesn't." (Participant 6)*

4.2.1 Staffing

All participants spoke highly of the staff that currently worked on campus, some spoke of how the current staff gave them piece of mind of how well their relatives were being cared for.

> "*For me to leave my daughter anywhere I have to know myself in order not to crack up and sleep at night and have a decent mind that she is being well cared for. And I have that where she is at the moment I have that. Decongregation to smaller settings- you would have to have the right people with her because she*

can't communicate if she likes something or doesn't or if she doesn't get on with someone or doesn't". (Participant 1)

One participant spoke of how her relative's life had improved since moving from dispersed housing in the community to the campus-based setting. The participant spoke of how the staff responded to the resident differently in the campus-based setting.

"The first time we brought him back and the [staff] welcome was- "welcome home [name]" and that wasn't the kind of welcome he would get in the residence in the community…. everyone of that staff knows him and there are quite a number of them..." (Participant 2)

Some participants spoke of how consistency of staff was particularly important for their relatives who cannot communicate verbally and that they perceived that there would be agency staff used more regularly in the community.

"...that being cared for by staff, not agency staff every few minutes that doesn't know the mannerisms of the children and the setup, that won't work. Consistency in staffing is a massive thing, that's eating its way into residential settings. I have a big fear about that. They are [staff] are brilliant there in [current campus based setting]". (Participant 1)

Participants were particularly concerned for the needs of their relatives who cannot communicate verbally and how important it is to have staff that know them well supporting them.

*"I mean they are very devoted the staff that are there. It's like a calling for them and I believe that would be like that that in a group home, a lot of the staff coming and going. I don't want someone leaving a little manual about [relative] to find out what he likes and dislikes…" (*Participant 6)

Participants also spoke of how a lot of the staff had been working in the campus-based setting for a long time and they felt that their relatives were loved by the staff.

*"I know they are genuinely mad about [relative] and we just know the staff and it's a safe environment for them... girls on the units are amazing and the care they give is brilliant." (*Participant 3a)

"….that has been their years know them and do everything to suit them and their great. We are blessed, blessed to have many of the girls that have been there years…." (Participant 5)

"….we are just so blessed that [relative] can be himself and with professionals who are paid to look after him and that his medical needs and meaningful day needs are met." (Participant 4)

One participant recounted a story of a resident who had lived in the campus-based setting and was moved to dispersed housing in the community with unfamiliar staff which had a huge impact on her behaviour which now comprises the safety of the staff and the residents own safety.

4.3 Safety and Independence

All participants cited the increased safety residents experienced living in a campus-based setting. All participants spoke of how their relatives had reduced safety awareness, in particular in relation to road safety.

> *"Now, he can just walk out his door [on campus based setting] and no car is going to hit him. He has enough awareness that he wouldn't go out the front gate, but he doesn't have road safety awareness, and we have done loads [training] with him, loads of independent living skills he still doesn't have the capacity to keep himself safe. Especially if he was in bad form or he is a big day dreamer he could just walk and keep walking that would be a big safety issue. So straight away you are locking the front door if he was out in the community."(Participant 4)*

Participants also spoke of how the campus-based setting provided opportunities for independence. Although some of the participants' relatives were wheel chair users some spoke of other residents whom they knew that could walk independently on the grounds of the campus-based setting.

One participant spoke of how her relative's independence had greatly increased since he moved to a campus-based setting.

> *"....when he was in residential in [dispersed housing in local townland] he went out to a day service and he came back and then he was, like he was in prison. He couldn't go out and he was frustrated, very frustrated, they had a duty of care to him and I understand that. But he wants this freedom and he has that now in [current campus based setting] he can walk around, or cycle around the campus, the gate is opened and it's just a different type of care too." (Participant 2)*

Participants who spoke about their relatives who were wheelchair users had limited experience of the resident's independence in relation to leaving their residence unaccompanied. However, many of these participants' recounted stories and experiences of other residents who experienced independence in the campus-based setting and the impact that a move to dispersed housing would have on the safety and levels of independent of them residents.

> *"....unfortunately from talking to some of the other family members about their loved ones, even when they go home on weekends, sometimes their parents have to keep the front door locked because they would just literally open the door and fly out onto the road." (Participant 6)*

Similarly, another participant spoke of how her relative's independence is reduced when he goes home at weekends. The participant also spoke about how her relative was not dependent on staff to accompany him, where he would be dependent on staff in the community. This participant spoke about her relative's sense of freedom. The participant spoke of how restricted her relative would be in the community and how being dependent on staff could cause behavioural outburst as the resident has poor waiting skills. The participant stated that her relative would not have any independence in the community as he would require constant supervision in relation to positive behaviour support and support to remain safe.

> *"My [relative] can stay in or go out, its flexible and it's not dependent or whether there's a staff there at the exact time he wants to go out, he can just go out in the campus based setting. If he was in a house, where there might only be 3 or 4 people on working he can't go out on his own like he can now. He has more independence now, we have lived in [a different country] and [different town] with him and the doors have to be locked, he would just walk out and straight in front of a car, so straight away his independence is taken away. Now, he can just walk out his door [on campus based setting] and no car is going to hit him." (Participant 5)*

4.4 Choice

The participants agreed that people should have the choice whether they want to live in the community or stay in their current campus-based setting. Most participants interviewed were not adverse towards the "Time to Move on from Congregated Settings" report and many identified the positive aspects associated with community living for some people, however participants perceived the strategy as a one size fits all approach which may not be appropriate for some people.

> *"....I think if they can tell what they want, they are entitled to go wherever they want to go or whatever suits them or their families but it shouldn't be forced upon us or forced on them where they should go or shouldn't go. I mean, like, we can pick a nursing home for ourselves, we're not told where to go when we get disabled or older, so I really don't think that my [relative] should be told now where to go or somewhere he doesn't want to go, am, so I think he has a right and other people in the community or congregated settings have the choice to go or stay if they want to." (Participant 2)*

In contrast two participants spoke of how the "Time to Move on from Congregated Settings" report and the proposed moves to dispersed housing in the community has and continues to ignore the wishes and choices of the residents, particularly if their choice involves staying in a congregated setting. This participant spoke of how the service provider had approached her relative and asked him if he would like to move to the community and that he had communicated several times that he does not want to move and that he wants to stay where he lives now.

> *"....No one seems to listen to him, they all say it's about choice, but when he is well able to say what he wants and he is well able to say what he wants. He told us that he doesn't want to leave and he reported that back to us. When he says he doesn't want to, and that is part of the time to move on policy, the choice should be integral. That's his choice; I don't see why that's not being considered. It's like that's his choice if it's going the way of the decongregation but it's not their choice if they want to stay where they are." (Participant 4)*

Another participant spoke of how the report highlights choice as a central component of the decongregation policy. However, the participant highlights that the report offers no choice to stay in a congregated setting and that the only option provided for residents is to move out to dispersed housing in the community.

"And I think it's actually unfair and I hate the hypocrisy at the heart of it, 'cos it's talking about choice. But for something to be choice you have to give more than one option. And the only option here is that you move out, if [relative] was able to speak, he might well turn around and say I love the people I have been living with for the past nearly 40 years, that I'm really happy being part of this community and living here. So, you know if he could say that, but this policy saying he has the choice to live with whoever he wants it's also mandating that he leave. So I actually think it's complete hypocritical." (Participant 6)

4.5 Lack of community supports

All participants spoke of how they perceived that there is a lack of supports in the community for people with disabilities. Majority of participants cited this as a reason for not wanting their relative to move to dispersed housing in the community. Many participants recounted stories of people living in the community who are not getting the supports they require.

"There's people out there that can't even get speech therapy so for people to say they will be supported in the community, they won't. We know they're not going to be supported, so how could we say in our right mind, ya it's ok for [relative] to go into the community when we now he might only get a visit once a week. Like we have physio every day for [relative]. Realistically, are you gonna tell me that the physio would call everyday if he was in a community house, no they won't." (Participant 3a)

Three participants spoke of how a large proportion of people with intellectual disabilities who were living in the community were lacking support services. They spoke at length about how money was being spent needlessly on decongregating those who don't wish to move instead of being spent on those who need residential placements.

*"It kinda strikes me like, that the most people, the people with disabilities in Ireland who have no service whatsoever, like with extortionate waiting lists for assessments of needs and all this type of stuff. And I just see that all this policy is gonna do is take away services from the only portion of the disabled population that actually has them, I think that's what it's gonna do and I think that's absolutely desperate."(*Participant 6)

Two participants cited a lack of transport in the community as an issue if residents were to move to dispersed housing in the community. One participant spoke of how her relative has a bus specifically for his unit currently and she feared that he wouldn't be supported to access the community as often due to limited transport.

"....if he was put into a small house somewhere, even on his own somewhere like [local towns] wherever, I don't know how long he would retain a

bus service. I don't know would they give a bus to every house or would people have to bring them in their own cars and then there would be all issues around that, insurance and modifying the car and… I just think his world would shrink and I think it would be an absolute tragedy." (Participant 6)

Five out of seven participants cited that a move to the community would limit their relative's access to a swimming facility. They spoke of how community pools are inaccessible to wheelchair users due to a lack of hoist equipment. They also said that community pools would be too cool for residents. All five participants spoke of how the on-site swimming pool benefitted their relatives due to the accessibility or the warmer than normal heated pool.

"….they need to have hotter water so that their muscles start to relax and that they can do all their physio inside in the water. But being told ya go into the pool and there will be a hoist put into the pool in the [local hotel] I mean, the noise in [the local hotel] for someone with autism is actually frightening. So it's just assuming that you can just plonk people wherever and it's not realistic." (Participant 4)

All participants spoke positively about the existing supports on-site at the campus-based setting. Some spoke of how they felt these services would not be as accessible if living in the community. Participants spoke at length about the lack of access to healthcare services in the community and the complex needs of their relatives and how these complex needs were being met in their current campus-based setting.

"So he's had onsite speech and language therapy, occupational therapy, massage, physiotherapy, psychology, psychiatry, dentistry, weekly visits by a GP and then the heated hydrotherapy pool which is a massive one for [relative] because he has spastic quadriplegic so it's important for his muscles. Now that's not available anywhere else so if [current campus based setting] closes out there like they're planning to I don't know where he is supposed to get that." (Participant 6)

One participant spoke of how if the support services were available in the community that they would not require residential services but would have their resident live at home with them with the right supports. The participant spoke of how she did not want to have her relative living in dispersed housing in the same town as his family but without the same care and not living with his family.

"We feel like if he goes out to the community, like realistically if he was out in the community we would have him at home, you know what I mean, if we had the proper services for him. We know we are not going to get the services out in the community, sure if we did he would be at home." (Participant 3a)

Another participant spoke of how the State is wasting money on decongregation instead of creating new residential placements for other people with intellectual disabilities.

"It kinda strikes me like, that the most people, the people with disabilities in Ireland who have no service whatsoever, like with extortionate waiting lists for

assessments of needs and all this type of stuff. And I just see that all this policy is gonna do is take away services from the only portion of the disabled population that actually has them, I think that's what it's gonna do and I think that's absolutely desperate." (Participant 6)

4.6 Community Inclusion

Many participants spoke of how their relatives regularly access the community. One participant spoke about the amount of support it takes to facilitate community access for her relative. Two people are required to transport him; she discusses the fact that if he were to live in dispersed housing in the community that it would not increase how often he accesses the community as staffing would still be an issue. Similarly, other participants spoke about their fears that adequate transport would not be provided if their relatives were moved to dispersed housing in the community.

"....meet out in the community, meet out for coffee sometimes and he goes out with his carers, he goes out with the nurses, he goes out with his buddies where he living. He is out in the community often……. The amount of staff that it would take to get him out- they wouldn't give him that. It takes two staff to get him out. There are constant cutbacks." (Participant 5)

Similarly, another participant spoke of her fear that her relative might not get to access the community as often if he lived in dispersed housing in the community.

"....I know they are in the community too but you are dealing with a smaller group, smaller staff and everything and it could become a little closed room in a very busy area. That's my worry that you are in the community but are you really in the community. It's all very good all well to say that you are included but are you." (Participant 4)

The same participant spoke of how the general community works and how some residents may find it difficult. The participant spoke at length about residents with auditory and sensory needs, particularly for residents with autism and how difficult they would find being in the community all the time.

"I think it's so engrained in the community and how it works that it's almost disables our family members more. Because everything is built, everything is set up and works for everyone else but might not work for my [relative] or someone else's relative. They're not going to change it..... So it's just assuming that you can just plonk people wherever and it's not realistic." (Participant 4)

Many participants commented on how they feared their relative may experience isolation if they were to be moved to dispersed housing in the community. Some participants spoke of they considered the campus-based setting a community of it's own but also how connected residents were with the local community. One participant spoke of how her relative goes out on the bus regularly to neighbouring towns and how well known he is locally.

"*....so I think actually think it would be like taking [relative] from his community which is a community, not that advocates or anyone recognises it like* *that but it is his community and it would actually be isolating him. Putting him into isolation and narrowing his world so much, because where he is now, he is part of a really big community*." (Participant 6)

4.6.1 Impact of the severity of impairment

Five out of seven participants agreed that living in dispersed housing in the community could be beneficial for some people and that they were not opposed to people with intellectual disabilities living in dispersed housing in the community.

One participant spoke of how the "Time to Move on from Congregated Settings" report was a one size fits all approach which does not take into account the needs of the residents. The participant also spoke of how someone with more ability could live successfully in the community and agreed that people should be given a choice.

> *"One size doesn't fit all. It's good for some people who have some bit of, am, can get around themselves. Someone who is highly dependent on others to survive, breath, to eat, no."* (Participant 1)

Many other participants referred to the report as a one size fits all approach. One participant spoke of the need to close some institutions but refuted that the campus-based setting where her relative now lives is an institution. She did not discuss the level of impairment or disability specifically but she did comment on how her relative's behaviour and how that affected his suitability to live in the community.

> *".....it's a fabulous report and I admire the people who put it together. But it is not suitable for everyone and that's where it has fallen down, one size does not fit all. I have experience of my [relative] being in residential care in the community and now he is in residential care in a congregated setting so he is very happy there. When he was in residential care in the community he was, we were constantly being called, ah, being told [relative] is gone in to the psychiatric hospital, and he's in there for a few days and then he's out again and this was going on. At another stage they had to move all the residents out of the house because he was a danger to the residents, he has challenging behaviour*." (Participant 2)

Similarly, other participants spoke of how the suitability was individualised to the person and their personality.

> *"It's personality based and it is very individualised, I couldn't say no one is suited to campus based settings or no one is suited to community living. Community living would be fantastic for some people and also if it's done correctly it could be amazing and I can see that. And I would be one of the family members who would be you know, both would suit, I know there's a need for every kind of setting as people are so individualised and needs are different."* (Participant 4)

4.7 Intentional communities

Many participants spoke about how they considered the campus-based setting as a community. One participant spoke about how campus-based settings should be improved to achieve community inclusion.

"Nothing is gonna be perfect, but in an ideal world I think the campus based setting is better. Because my idea of an ideal campus based setting you would have people from the community working in shops on the campus, that would be my dream, where people with disabilities could work on campus but if they didn't there would be people to back them up. My ideal now, if I won the euromillioms would be to have a café on campus and that locals would come to it and there would be a playground so you're bringing the community in, more of an integrated community, like a reversal integration." (Participant 4)

"practical things like the hydrotherapy pool, am just that, all the sensory care, they have such a state of the art facility, the massage, the occupational therapy, am even the weekly visits by a GP…… But for [relative] I feel what he deserves is to have it recognised that where he lives and where he has lived all his life when is not at home is a community, that's it's not an institution." (Participant 6)

4.8 Conclusion

This study revealed that the families of people with intellectual disabilities living in campus-based settings experience overall satisfaction. The study found that the family members are not happy with a proposed move to dispersed housing in the community as they perceive that community living does not provide the same opportunities for residents as the campus- based setting. The findings also raised some important considerations which will be addressed in the following chapter.

This concludes the summary of central findings from this research. The following chapter discusses these findings in relation to decongregation, literature and the research question.

Chapter 5: DISCUSSION

5.1 Introduction

This study aimed to explore the impact of a proposed move to dispersed housing on the perceptions and attitudes of family members of people with intellectual disabilities. The main themes that were identified in the study will be discussed in this chapter. These findings will be discussed in contrast to the existing literature reviewed in Chapter 2 and similarities and contradictions will be identified and discussed.

5.2 Satisfaction with the quality of existing service

At the initial stages of this research, particularly during the review of existing literature, a number of gaps in the existing research were identified. One of the most evident gaps was in relation to the absence of research which explored the perspectives of residents or family members. Another gap identified was the lack of research carried out around existing facilities and the perspectives of residents or their families on these.

A large body of post-deinstitutionalisation evidence does support the hypothesis that moving from an institutional residential setting to a community residential setting is associated with an improved quality of life for adults with intellectual disabilities settings (Emerson & Hatton, 1996; Jansen et al, 2006; Melville et al, 2006; Young et al, 2001). It is hardly surprising that research found isolation and segregation among residents who lived in larger scale settings with a lack of access to the greater community. However, there has been little consideration for purpose-built campus-based settings which have quality service provision and where residents have greater access to the community.

Although some researchers have advocated for community living for all people with intellectual disabilities, Emerson et al (2000) acknowledged that campus-based housing offers different, although not inferior quality of life to residents in comparison to dispersed housing. Nonetheless, the research does not detail any of the positive aspects or potential benefits associated with living in a campus-based setting.

All participants of this study discussed at length their satisfaction with the existing campus-based setting and outlined the positive aspects of residents lives directly associated with living in a campus-based setting. Some of the positives that family members identified were that residents appeared happy and had a sense of belonging and experienced increased safety.

All participants cited that the existing facilities had more to offer to residents than community facilities, including a hydrotherapy pool, on-site physiotherapy and occupational therapy as well as access to a general practitioner and nursing services.

This study also provided an insight into the resistance of families towards the decongregation of their relatives. Although this study was conducted with a small sample size it could be assumed that these findings are indicative of why other families have resisted to decongregation due to similar concerns and fears across the country in recent years.

5.2.1 Staffing:

Emerson (2004) found that people living in cluster and campus-based settings were more likely to be supported by fewer staff and experience change of staff more frequently and were subject to increased restrictive practices. However, in stark contrast this research found that fears about reduction in staffing in the community were one of the main reasons of resistance against proposed moves to dispersed housing.

All participants spoke of the importance of continuity of staffing and how this impacted positively on the lives of the residents. Participants also commented on the staff retention and how a lot of the staff had been working with their family members for a long time and were able to understand and communicate with their relatives despite some of their communication difficulties.

"We don't want strangers in and out, [relative] is hard to understand but the girls [current staff] knows what he is saying so they can understand him and he loves chatting. We like that he is safe and that he is with people we know, the care has always been there and we have always had good support." (Participant 3a)

Similarly, Doody (2011) who carried out research with family members of residents who had moved to a campus-based setting found that families reported that the staff had improved the involvement of residents and families in the care of individuals.

Family members voiced their concerns about what they perceived the staffing would be like in the community. Some participants spoke of their fears of unfamiliar staff, in particular agency staff working with the residents and there being a lack of consistency among staff members.

"Consistency in staffing is a massive thing, that's eating its way into residential settings. I have a big fear about that." (Participant 1)

Family members also commented on how residents experienced "freedom", "independence" and "choice" in the campus-based setting. This is inconsistent with Emerson (2004) findings which suggested that residents were more likely to experience restrictive practices within a campus-based setting.

One other concern families voiced in relation to staffing was how in a campus-based setting the care staff are employed to do exactly that, care for residents. A number of participants were concerned that if their relatives were moved to smaller homes in the community, that the staff would be doing other chores, such as cooking and laundry. Participants were concerned that this would take away from the level and quality of care experienced by their relatives.

"I suppose if he was to move out, there's gonna be different people in and out of there and we know other houses [in the community] the staff have to cook the dinner, wash the clothes, do the cleaning so they're not caring for the lads then. In [current campus based setting] the staff is there with [relative] and the lads and they are making sure they are dressed and showered or whatever. The night staff do the washing and whatever, their food is prepared. The staff would have to do all that. He is safer where he is." (Participant 3a)

As the researcher has experience working in smaller group homes in the community, the researcher would agree with this perspective, that certainly staff would be responsible for the household duties and this could compromise the level of care that is provided to residents. This is particular true with residents who have more complex needs where constant supervision is required for residents who may have medical conditions such as epilepsy and suffer seizures.

5.3 Safety and Independence

The existing research does not focus on the safety or independence levels of residents either in a campus-based setting or in dispersed housing in the community and appears to focus on quality of life and community inclusion only. However, a strong theme that emerged from this research was the level of safety and independence experienced by residents in the existing campus-based setting.

All participants made reference to residents being able to safely walk or cycle on the grounds independently as being a huge advantage of living in a campus-based setting. Participants also spoke of how this would be unachievable in the community due to some residents' lack of basic safety awareness, e.g., road safety.

One participant explained how her relatives' independence was immediately restricted when he came to stay in her home in the community due to safety concerns. The participant explained in contrast how her relative could leave his home independently in the campus-based setting and visit the church or the day service on-site as he pleased. The participant cited this as a huge barrier for her relative to live successfully in the community.

"Now, he can just walk out his door [on campus-based setting] and no car is going to hit him. He has enough awareness that he wouldn't go out the front gate, but he doesn't have road safety awareness, and we have done loads [training] with him, loads of independent living skills he still doesn't have the capacity to keep himself safe. Especially if he was in bad form or he is a big day dreamer he could just walk and keep walking that would be a big safety issue. So straight away you are locking the front door if he was out in the community."(Participant 4)

There is little discussion about safety and independence within the existing literature. However, this emerged as one of the main concerns of participants of this research. It is important to acknowledge for some people with intellectual disabilities their safety and independence may not be compromised if residing in the community. However, it is also important to recognise that not all people with intellectual disabilities have the capacity to keep themselves safe, but still have the desire to have independence. This needs to be considered when choosing appropriate living arrangements. This is a huge area for further research in relation to decongregation.

Unfortunately the lack of awareness or consideration around these issues is not unique to Ireland. Bigby (2008) found that in countries such as Australia and New Zealand the policy was changed around deinstitutionalisation and more campus-based settings were developed to facilitate moving people who had already moved to dispersed housing, back into these congregated settings. Particularly those with challenging behaviour were found to live more successfully in a campus-based setting rather than dispersed housing in the community.

Ironically, the "Time to Move on from Congregated Settings" report (HSE, 2011) outlines the international experience of decongregation and how successful it has been. However, information in relation to the countries that have reverted back to congregated settings has been omitted from the report.

Interestingly, one participant whose relative lived in dispersed housing in the community spoke of how her relative's life had improved drastically since he moved to the campus based setting. When living in a shared house in the community, other residents had to be moved out due to his challenging behaviour and he was confined to his home a lot of the time. The participant says that since he has moved to the campus-based setting that he is experiencing independence that he has never had in his life and that his family are reassured that he is safe and not comprising the safety of other residents.

"We reverted back to the congregated setting. We know from his, he is a totally different person now to when he was in the house in the community. He is much more aware of his surroundings, he is chatty, he knows people, he knows all his carers, and he knows everyone in his house. He never knew them when he was in the house in the community. He wasn't part of that house at all and I'd say didn't want to be part of the house, as I say he was locked into it. It was a prison for him." (Participant 2)

The participant spoke of how she admired the "Time to Move on from Congregated Settings" report but that no one should be forced to move to the community and that residents should be given a choice to stay in the congregated settings or move to the community, supported by their family.

5.4 Choice

The "Time to Move on from Congregated Settings" report suggests that the choices of people with intellectual disabilities is integral and that the policy is facilitating choice. "They should be able to exercise meaningful choice, equal to that of other citizens, when choosing where and with whom they live" (HSE, 2011: p.12). However, the report outlined that the primary aim is to stop admissions and close all congregated settings. Participants highlighted this and accurately highlighted that the policy does not allow for choice, if that choice is for residents to remain in their current “congregated” setting.

One participant spoke of how her relative was asked if he would like to move to the community by a member of the service provider’s management team, without prior knowledge or consultation of the family and was reported back by the resident. The resident had told management that his choice was to stay in his current campus-based setting and that he did not want to move to the community. The participant says that this decision is not being accepted by management even though that decision is based on his choice.

Similarly, another participant outlined how in reality residents are not being given choice as only one option is being presented to them and that is to move out to the community. The participant suggests that this cannot be considered as a choice if only one option is presented to you. Most participants cited that they felt a move to the community could be successful for some, but that it is an individual choice to be made by the residents and their families. Participants were not opposed to the process of decongregation but that it should not be a one size fits all approach.

“Community living would be fantastic for some people and also if it’s done correctly it could be amazing and I can see that. And I would be one of the family members who would be you know, both would suit, I know there’s a need for every kind of setting as people are so individualised and needs are different.” (Participant 4)

One participant even spoke about how she had experience of her relative living in another congregated setting and she considered that congregated setting an institution.

“...it was a congregated setting, it was a dreadful, dreadful place but the staff more than made up for what lacked in the building and the home there.” (Participant 2).

When the researcher asked the participant what were the differences between an institution and the current campus-based setting she remarked on the difference in the atmosphere of the campus-based setting. She outlined how her relative felt he was a part of his home.

“The institution was a big building; it was an old psychiatric hospital. They had to go downstairs, the older people to have their meals, it was terrible. The congregated setting he is in now is like, they have their own homes and he likes meeting the other people there and it’s just different.” (Participant 2)

The topic of choice for people with intellectual disabilities is under researched and understandably so as there are a number of barriers to addressing this gap in research, communication difficulties being one. However, it is evident from this research that residents are not been given a choice to choose where they would like to live. The Time to Move on from Congregated Settings report (HSE, 2011) has already decided that all 4,000 people residing in congregated settings will be moved out and no new admissions will be made. Therefore, it is evident that the HSE have already made the choice for residents. What if their choice is to remain living in their current campus-based setting with their peers who they have lived with for many years? (I don't know if a question is really suitable here?) Well, they can forget about that as the HSE have already decided that dispersed housing in the community is better for them.

5.5 Lack of supports in the community

Most participants cited lack of supports in the community as a reason why they did not want their relative moved to dispersed housing in the community and this was further discussed in relation to the theme of satisfaction of existing services. They also discussed that they had huge concerns in relation to what was available in the community. Some spoke of how the media has been highlighting that many children and adults who are currently living in the community are without basic services and residential placements.

It is widely accepted that Ireland is currently facing a housing crisis as well as a crisis in provision of residential placements for children and adults with intellectual disabilities. This knowledge of lack of supports available was apparent when interviewing participants. Participants spoke of how they knew people who did not have support services for their children, in particular older parents caring for their children with disabilities at home.

> *"We know of people who can't get services, of older woman and men in their 70's and 80's with 30, 40 and 50 year old children that have behavioural issues and they can't control them and they are stuck at home."* (Participant 3a)

Interestingly, participants spoke of how other people with intellectual disabilities who were living in the community were experiencing poor supports. The concern around the lack of residential placements for people living at home was cited by many participants.

The existing literature does not explore the levels of supports available and if there is any difference in supports between community and campus-based settings. This is an area which could be further researched to gain a clear picture of the issue that people may face if they moved to dispersed housing in the community.

Interestingly, one participant spoke of how if the supports were available in the community they would have their relative residing at home with them. It could be suggested that if the government were in a position to provide supports in the community to all 4,000 people living in congregated settings then national media would not be highlighting areas of service absences and emergency only residential placements.

Participants also spoke about how they feared that moving to dispersed housing would impact on the resident's access to the community. Participants anticipate that a lack of availability of transport would impact on residents accessing the community.

All participants cited the lack of support in the community as one of their main concerns about the proposed move to dispersed housing. Participants spoke of the lack of physiotherapy services and healthcare services in the community.

All participants interviewed stated that they were happy with the current living arrangement for their relative. One participant spoke at length of how she perceived decongregation as wasting money.

"And I just see that all this policy is gonna do is take away services from the only portion of the disabled population that actually has them, I think that's what it's gonna do and I think that's absolutely desperate." (Participant 6)

This is an important point to highlight as O'Brien (2013) found that there were over 2,000 children and adults with disabilities assessed as requiring a residential placement, one can only assume with disability funding decrease that this number has increased in 2019. It is evident that the demand exceeds the supply, so decongregation could intensify the lack of residential placement as the HSE will be preoccupied moving the 4,000 people to dispersed housing in the community. There appears to be no consideration taken for the people who are living at home with their parents and their "community integration" or "choices".

There is also the issue of people with intellectual disabilities being inappropriately placed in hospitals and nursing homes as a result of the lack of residential placements. One participant spoke at length of these issues and highlighted that on one side of the HSE they are moving people out of congregated settings but on the other side they are moving those who lived in the community all their lives into congregated setting because they do not have the services in the community to support them.

"...its absolutely crazy that at the moment you have one section of the HSE who are trying to move people who have had institution care all their lives out to the community and at the same time then you have another fraction that are taking people who have lived in the ordinary community all their lives, who are now adults and you're putting them into an institutionalised type care which is like a nursing home essentially. So the whole thing is bonkers like." (Participant 6)

This is in direct contrast to the "Time to Move on from Congregated Settings" report (HSE, 2011) and also the New Directions implementation plan (HSE,2012) which sets out that people should get the right support to live where they choose and that these should be good quality supports. The implementation plan also outlined how people with intellectual disabilities should be included in their communities. However, it is unfortunate that people aged in their 30's and 40's are now being inappropriately placed in nursing homes as there is no alternative placements available for them in the community.

5.6 Community Inclusion

This research identified that family members felt their relatives were already a part of the local community outside of their campus-based setting and spoke of how they felt that their community inclusion would not increase with a move to dispersed housing in the community. This supports the existing literature of which many authors found that moving people with intellectual disabilities to the community does not necessarily lead to increases in levels of social contacts or community inclusion (Beadle-Brown et al, 2007; Hall &Hewson, 2006; Forrester-Jones et al, 2006; Young, 2006).

One participant who has experience of her relative living in both dispersed housing and who is now residing in a campus-based setting spoke of how he was not involved in the local community in any way while he was living there and how this has improved since he moved to the campus-based setting. She commented on how isolated he was when he lived in the community and how he had very limited community interactions.

> *"But I feel that even when he was in the house in [the community] he certainly did not communicate with any of the neighbours on either side, there was no such thing as community living because it was going back into his house at night and it was like going into prison. It was in the middle of the town, he wasn't happy."*

Many participants spoke of how their relatives are well known in the local community and are supported by staff to access the community regularly. Forrester-Jones et al (2006) suggested that there are many challenges for people with intellectual disabilities to live in the community successfully. Similarly, these challenges emerged from participants of this study.

All participants interviewed cited accessing a suitable swimming pool in the community as a barrier to living in the community successfully. Participants suggested that it was impossible that their relatives could access swimming pools in the community due to the lack of hoisting facilities for people who are wheelchair dependent and the reduced temperature of typical community pools. Another participant cited her relatives challenging behaviour, auditory and sensory issues as a barrier to accessing local community facilities.

Many participants spoke of how they don't feel that a move to the community would improve their relatives' life. Some spoke of how the proposed move to dispersed housing would merely be a change of physical placement and may actually result in isolation and would act as a barrier to community access and further limit community interactions.

> *".....in the community too but you are dealing with a smaller group, smaller staff and everything and it could become a little closed room in a very busy area. That's my worry that you are in the community but are you really in the community. It's all very good all well to say that you are included but are you."* (Participant 5)

5.6.1 Impact of the severity of impairment

Several studies have found that severity of a person's intellectual disability also plays a huge role in the difference of the quality of life experienced by people within the community (Abbot and McConkey, 2006; Smith et al, 2005). Findings suggest that those whose intellectual disabilities were considered severe experienced less social inclusion, did not participate in the same levels of meaningful activities and experienced less choice (Abbot and McConkey, 2006).

This is especially true for people with more complex needs such as challenging behaviour. It is widely acknowledged that some people with intellectual disabilities with high support needs and challenging behaviour can be supported successfully in the community; however, improvements are not experienced by all (Mansell and Beadle-Brown, 2009). This was evident for one resident in which the participant spoke of how her relative's life was extremely limited when he lived in the community.

*"When he was in residential care in the community he was, we were constantly being called, ah, being told [relative] is gone in to the psychiatric hospital, and he's in there for a few days and then he's out again and this was going on. At another stage they had to move all the residents out of the house because he was a danger to the residents, he has challenging behaviour". (*Participant 2)

5.7 Intentional community

Some participants stated that the existing campus-based setting should not be considered as a congregated setting or an institution but as a community. Participants cited that residents had a sense of belonging within the campus-based setting but still had strong links with the local community. This supports the view that as a society we should focus on the sense of connectedness rather than physical placing people in the community (Chowdhury & Benson, 2011).

Participants spoke of how happy their relatives were living in their current campus-based setting. Some participants suggested that policy makers should focus on improving the services that are currently successful such as the campus-based settings and create an intentional community. One participant spoke of what she would think would be the ideal living arrangement for her relative.

"Because my idea of an ideal campus based setting you would have people from the community working in shops on the campus, that would be my dream, where people with disabilities could work on campus but if they didn't there would be people to back them up. My ideal now, if I won the euromillions would be to have a café on campus and that locals would come to it and there would be a playground so you're bringing the community in, more of an integrated community, like a reversal integration." (Participant 4)

Many authors have suggested that intentional communities provide the opportunity for people to integrate with other people of similar interests (Cox & Pearson, 1995 and Cummins & Lau, 2003, Chowdhury and Benson, 2011). This was also evident in the research as some participants spoke of the importance of the peer to peer relationships among the residents, some of whom had been living together since infancy. One participant commented on how he felt that his relative was safer residing with people of similar abilities.

> *"Also, if she was put with people with abilities, we wouldn't know if she was being bullied or harassed or what."* (Participant 1)

Many authors have suggested that intentional communities create better outcomes, particularly for those who have severe or profound intellectual disabilities. It is evident in this research, particularly from the contribution of one participant who had experience of her relative living in both community and campus-based settings, that campus-based settings have the potential for creating better outcomes for residents.

5.8 Conclusion

It is evident from this research that there are still a number of gaps which could be explored to provide a deeper insight and understanding. Under researched areas such as the quality of existing settings and the levels of safety and independence experienced by people with intellectual disabilities in both congregated setting and community settings are areas for future research.

Some of the findings of this study have the potential to challenge some authors' perspectives that community living in ultimately better for all people with intellectual disabilities. This research has illuminated the fact that no one size fits all has the ability to meet the complex needs of every person with an intellectual disability. The author is conscious that it cannot be assumed that one living arrangement is superior to the other for people with intellectual disabilities, but it can be contested that one living arrangement can be superior to another for an individual, dependent on their individualised needs and choices.

Chapter 6: CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

The "Time to Move on from Congregated Settings" report (HSE, 2011) had intended in moving all 4,000 people who were living in congregated settings to dispersed housing in the community by 2018. Now in 2018, less than half the residents have been moved to community settings. Some family groups of those residing in the congregated settings continue to campaign against decongregation of their relatives. The overall aim of this study was to gain insight and understanding of the impact of proposed move to dispersed housing in the community on the perceptions and attitudes of family members of people with intellectual disabilities residing in congregated settings. The objectives of the study were addressed by interviewing seven family members of people with intellectual disabilities currently residing in a congregated setting.

6.2 Recommendations

Further research should be conducted with residents and their families who are residing in congregated settings and their perspective should be used to educate policy makers to inform the service delivery.

The Health Executive should focus on assessing the existing congregated settings on an individualised basis and not on the number of residents alone. The settings should be assessed to determine if the service provision is of good quality or not.

The HSE should then focus on improving and developing some of the congregated settings which are deemed to be providing good quality care. A sense of connectedness should be prioritised instead of the physical move to the community.

The working group involved in the "Time to Move on from Congregated Settings report" (HSE, 2011) should facilitate a consultation with residents and families to undercover the needs and wishes of residents and revise the strategy. The mandate of closing all congregated settings and stopping new admissions should be reviewed.

Availability of the support services in the community should be assessed before any residents are transitioned to community living. Creation of new residential places should be prioritised for those without services, who may be residing at home with elderly carers and those who have been inappropriately placed in nursing homes.

Decongregation as an approach should be reviewed. If people are residing in living arrangements of poor quality many options should be presented to the residents and their families. These options should deliver individualised supports and care, whether in the community or a campus-based setting.

It is important to acknowledge that while these recommendations may be challenging to implement, the strength of the families and their efforts to campaign for more than a ‘one size fits all approach’ may impact on policy makers more effectively than any research.

6.3 Conclusion

The study found strong opposition against proposed moves to dispersed housing in the community for their relatives. However, families highlighted that they were not opposed to the “Time to Move on from Congregated Settings” report (HSE, 2011) but advocated for a more individualised approach in which residents and their families would be offered the choice to stay in the congregated setting or move to the community. Although, majority of participants had positive views towards the policy, many referred to the report as a ‘one size fits all’ approach and described how the level of a person’s impairment and disability has an impact on the suitability of living arrangements.

The families cited many reasons why dispersed housing in the community would not be suitable for their relatives including the level of impairment and need for specialised services. The study found that all participants involved were happy with the current living arrangements and highlighted to quality of existing facilities in the campus-based setting as well as the quality of the staff that cared for the residents. Participants highlighted how there was no alternative in the community which would meet the needs of residents who had complex needs who used the on-site hydrotherapy pool. Participants spoke of how on-site physiotherapy and occupational therapy were important factors in their decision for their relative to remain residing in the campus-based setting, particularly for residents who had mobility issues.

All participants spoke about lack of services in the community and highlighted the current and varied crises facing people with disabilities and their families. Some participants found it concerning that the policy makers were focusing on their relatives who have the appropriate supports, albeit in a congregated setting, instead of implementing policy and funding towards creating residential placements for the people who need them.

The study also found that the families were particularly interested in the safety and independence levels experienced by residents and concerned at how this would be impacted if they lived in the community. Participants described how residents enjoy a sense of freedom and have the opportunity to walk/ cycle independently on the grounds of the campus-based setting. Some participants described how their relatives were more restricted when residing, even temporary in the community due. They described how doors in their homes were locked as their relative has very limited safety awareness and would walk in front of oncoming traffic.

Participants highlighted how they felt that their relatives were including in the local community, as the already accessed the community regularly, supported by staff. Other participants spoke of how residents had a sense of belonging in their current campus-based setting and that they considered that as a community. One participant recounted how her relative had lived in the community and was isolated and segregated but felt since he had moved to the campus-based setting that he was much more integrated. Overall, the family perceived the proposed moves to the community as having a negative impact on the quality of life of their relatives.

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APPENDIX A

LIT Dissertation Ethics approval Form

Please note if you do not obtain ethical approval in writing from your dissertation supervisor (which should be referenced in an appendix from your Method section) your project is likely to fail on ethical grounds. You should submit this form along with a copy of any data collection instrument, information sheets and informed consent forms (outlining participants' right to withdraw with no negative consequences).

Your Name:__Róisín Nic Ginneá____ Your **Project Title: "An exploratory study of the perspectives of family members on decongregation of relatives with intellectual disabilities"____** **Method of data collection** (circle): Survey Focus Group **Interview** Content analysis **Number of participants: ___6________**	**Yes**	**N/A**
1. Does your proposed research need initial clearance from a 'gatekeeper' (e.g. Local Authority, head teacher, college head, nursery/playgroup manager)? Have you indicated how you will negotiate this in your proposal? Please give details of any gatekeepers – I will be contacting the family members through a Facebook page which they have set up- the gate keeper will be the person who is the administrator of the Facebook page.		
2. Does your proposed research involve work with 'vulnerable' populations? Please explain your answer: (Does you sample include children less than 16 years old, school pupils and/or vulnerable groups. If so, say which special measures you have taken to ensure that they are not exploited. No as I will not be working with the people with intellectual disabilities, the research is limited to family members.		

3. Does your proposed research involve work with 'vulnerable' populations? Please explain your answer: (Does you sample include children less than 16 years old, school pupils and/or vulnerable groups. If so, say which special measures you have taken to ensure that they are not exploited. No as I will not be working with the people with intellectual disabilities, the research is limited to family members.		
4. Please indicate how informed consent will be obtained from your participants? Your consent letters/forms must inform participants that they have the right to withdraw from the study at any time. How will you do this? Informed consent is a central component of the research process. Seeking this informed consent will require a three step process. Initially, to identify willing participants, contact will be made with a committee which is made up of family members of people with intellectual disabilities. Contact will be made with this committee and details of the study will be provided which will seek willing participants to contact the researcher if they are interested in participating. Respondents will be provided with additional information in the context of an explanatory information sheet detailing the aims of the research and the role of participants including the amount of time needed to conduct interviews. When participants have been identified for inclusion in this research they will be provided with a consent form which will detail in plain language; • What they are consenting to participate in. • How to researcher will provide anonymity to participants. This will be achieved by concealing participants names and identifying them by using the term; participant 1, 2, etc. • Clarify that participants are free to withdraw from the research at any time without any consequence. • Details of confidentiality and safe storage of information. This will be achieved by storage of consent forms in a secure document file, which is inaccessible to the public. Participants will be asked to complete these consent forms and return them to the researcher which will then be stored in a secure place.		
5. Please explain your debriefing procedures: Provide contact details for researcher and supervisor. Participants will also be offered the opportunity to debrief immediately after interview.		
6. Are you proposing to collect video and/or audio data? If so please explain how you will protect participants' anonymity and confidentiality and how you will store the data? Audio Data will be stored on a voice recorder device which will be stored in my home and data will be deleted when the data is recorded successfully.		

Participants names will not be used to ensure anonymity, instead participates will be identified by numbers only.		
7. Does your proposal indicate how you will give your participants the opportunity to access the outcomes of your research (including audio/visual materials) after they have provided data? Please explain your answer: Participates will be given a copy of the research after it is submitted to LIT.		
8. Have you built in time for a pilot study to make sure that any task materials you propose to use are appropriate and that they are unlikely to cause offence to any of your participants? Explain your answer: N/A as the questions will be reviewed by supervisor prior to interviews.		
9. Is your research likely to involve discussion of sensitive topics (e.g. adult/child relationships, peer relationships, discussions about personal teaching styles, ability levels of individual children and/or adults)? What safeguards have you put in place to protect participants' confidentiality? Participates names will not be used to ensure anonymity. Safe storage of audio device to ensure confidentiality.		
10. Does you proposed research raise any issues of personal safety for yourself or other persons involved in the project? How do you propose to ensure your own safety and that of your participants? Meeting participants in a public location.		
11. Have you ensured (in your consent form) that participants are aware of who they should contact in the event that they have a complaint? Explain: Yes- contact details of LIT will be included in the consent forms.		
12. Have you attached a copy of any stimulus materials e.g. questionnaires / interview schedule etc.? N/A		

For Lecturer use:
Approved Not approved (please circle as appropriate)
Supervisor comments:
The above project can be regarded as: **Low Risk** Moderate Risk Permission Denied

Signed (Student): ______________________________ Signed (supervisor) ______________________________

Appendix B

Dear Participant,

My name is Róisín Mc Kenna and I am currently completing a Masters Dissertation in Social Care Management at Limerick Institute of Technology. As part of my course, I am required to complete a research dissertation. My chosen topic for research is *"What is the impact of a proposed move to dispersed housing on the perceptions and attitudes of family members of people with intellectual disabilities?".* I would be extremely grateful if you were available to take part in an interview when availability best suits you. The interview will take approximately 15 – 20 minutes to conduct.

Involvement in this study is completely voluntary and you may withdraw at any stage without consequences. All information will be fully confidential and ID codes will be utilised throughout the study for the full protection of you and your relatives. Any identifying features will be changed. If you would like to participate in this study, please sign the attached form.

If you would like any further information about this research, please do not hesitate to contact me on 0871354867or email k00118425@student.lit.ie. Furthermore, you can also contact my supervisor Matthew Cannon at matthew.cannon@lit.ie

Kindest Regards,

Róisín Mc Kenna

Appendix C

Consent Form

I, _________________ have agreed to take part in the above research project.

- I understand that I will take part in a 15 – 20 minute interview with Róisín Mc Kenna which will audio recorded.
- My participation is fully voluntary
- I understand that I have the right to withdraw from this process at any time.
- If I withdraw from the study there will be no negative consequences
- I am aware that I am permitted to view all research and transcripts that have taken place concerning my involvement. I can request a copy of the report from the researcher
- All information will be confidential and used for only the study
- I understand that ID codes will be used to protect my anonymity and confidentiality and names of people and places will be changed
- I agree that quotations may be used for the purpose of the research

I would like the pseudonym used for direct quotations from me to be ___________________

Signed: _____________________________

Date: _______________________________