Title	Exploring community living in Ireland: Experiences of ageing with and into disability
Author(s)	Loughlin, Emily
Publication Date	2019-12-16
Publisher	NUI Galway
Item record	http://hdl.handle.net/10379/15656

Exploring Community Living in Ireland:
Experiences of Ageing With and Into Disability

A thesis submitted to the National University of Ireland, Galway,
in fulfilment of the requirements for the degree of
Doctor of Philosophy

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October 2019

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Declaration

I, Emily Loughlin, certify that this thesis is my own work and that I have not used this work in the course of another degree, either at the National University of Ireland, Galway or elsewhere.

Signed: ________________________________

Acknowledgements

This thesis would not have been completed without the support and friendship of many people.

I am indebted to my main supervisor, Professor Thomas Scharf for his commitment, kindness and unwavering support. I never came away from a supervision meeting without feeling positive and encouraged. Tom believed in me when I doubted myself and in the end that made all the difference. I am also grateful to my other supervisors Professor Gerard Quinn and Professor Kieran Walsh. Gerard Quinn first introduced me to disability rights and afforded me many opportunities along the way. Kieran Walsh's door was always open and he offered steadfast support in seeing this thesis over the line. I would not have arrived at this point were it not for all three, who shaped and influenced my PhD journey in complementary ways.

The Irish Centre for Social Gerontology and the Centre for Disability Law and Policy provided me with a stimulating working environment and many lovely colleagues. I especially appreciate the kindness and generosity of Christine de Largy. I am thankful to my Graduate Research Committee for their insightful feedback and constructive suggestions for my research. I appreciate immensely the support of the National University of Ireland, Galway for providing the initial funding for this research, and the Irish Research Council for supporting the research thereafter.

I owe special gratitude to the older people with disabilities who agreed to participate in this study. They welcomed me into their homes and lives and shared so generously their time and stories. I will forever remember these encounters with fondness. I am also grateful to the expert stakeholders who recognised the value of this research and imparted their considered views on ageing and disability and helped me understand the nuances of policy.

I am fortunate to have wonderful friends who took an interest in my research and provided welcome distraction at other crucial times. In particular, I am thankful for Michelle, Eileen and Andrea - for knowing me so well and for all the good times we've shared. These past number of years have also brought new friends into my life and I am lucky to have met so many genuinely lovely people, not least Pui, Sinéad, Charlotte and Padraic, whom I now hold dear. There were lots of coffees, cakes and chats – foundation for great friendships that I hope will continue for many years to come.

My family are mentioned last in recognition of the special part they have played in this PhD journey. My parents, Myra and Jim, have always believed in me and encouraged me wholeheartedly in all my endeavours. I have relied on their sound judgement and have always been assured of their unwavering love and support. In Alison and Eric, I could never have wished for a better sister and brother. They have always been amongst the best parts of my life with their good humour and good advice and I would honestly be lost without them. Last but never least I would like to thank Tadhg. For always being there for me, listening to me, supporting me and even reading my thesis. *Fíorbhuíochas ó chroí, do gach uile ní, duitse mo stór, anois 's go deo.*

Abstract

This research examines the topic of community living for older persons with disabilities. This group comprises people who are ageing with disabilities, either lifelong or earlier onset, as well as people who are ageing into disability, having first experienced disability in older age. Community living is understood as encompassing elements of independent living, ageing in place and community inclusion. This research is contextualised by the life course whereby experience in later life is considered in light of the influence of transitions and turning points in earlier life.

An empirical study adopting a qualitative design and a two-phase approach was undertaken to address gaps in knowledge of the conceptualisation of community living at the ageing/disability nexus, as well as silos and synergies found in ageing and disability policy responses. Articulation of voice through biographical narrative interviews provided a basis for capturing authentic accounts of lived experience. Interviews were conducted with a diverse sample of 20 older persons living in community settings with physical, sensory, intellectual and cognitive disabilities. Semi-structured interviews with expert ageing and disability sector stakeholders were also carried out in order to contextualise the lived experience and to address issues concerning the existence of silos in ageing and disability as well as the potential for more holistic life-course policies for community living.

Findings from this research demonstrate that despite coming to experience disability at different stages of the life course, the overall understanding and experience of community living is quite similar for older persons with disabilities. This diverse group were shown to value community living across largely similar domains. The findings also offered a stakeholder perspective on issues of congruency and incongruence and the implications of these circumstances. As a whole, this research contributes to an encapsulating understanding of what community living means at the ageing/disability nexus. It also provides a rationale for bridging ageing and disability in both research and policy so as to develop more holistic policy responses that deliver better outcomes for this group occupying space across both sectors.

Chapter One
Introduction

1.1 Introduction

The growing diversity of older people is increasingly important for policy responses to social issues. A key group that is indicative of such growing diversity is older persons with disabilities. This group straddles ageing and disability and includes both people who are experiencing early onset, or lifelong disabilities, as well as people who are experiencing disability for the first time in older age. This group encompasses a wide spectrum of life course trajectories with broad variance of experiences, preferences and values.

For older persons with disabilities, community living is an area of social policy that is of particular relevance. Community living, encapsulating both living independently and being included in the community, spans the ageing and disability sectors and has relevance across the life course. Despite this, and despite that related policy will need to be responsive to life-course factors, existing structures often fail to consider the particular circumstances and needs of older persons with disabilities (Putnam, 2014). Furthermore, owing to a multitude of processes and forces, not least changing needs and fluctuating supports, both ageing and disability can present challenges to achieving meaningful community living.

While this raises questions about how people who are older and disabled experience and conceptualise community living, research has rarely addressed this topic for this group. As such, there are distinct policy and research gaps concerning the lived realities of community living and how to appropriately support older people with disabilities living full lives in their communities. Disability has a significant impact both at an individual level and at a societal level in terms of response to individual needs (Bickenbach *et al.*, 2017). As disability is likely to be a feature of life for a significant proportion of older people

(Kingston *et al.*, 2018b), the goal of policies should be to strengthen autonomy and wellbeing in relation to community living irrespective of disability (Henning-Smith *et al.*, 2018).

By way of introduction to this thesis, which sets out to address these issues, this chapter begins by contextualising the research within ageing and disability scholarship and policy and demonstrating a scientific rationale for this work. It provides a brief note on the terminology employed throughout the thesis. Following on from this my background and motivations for conducting this particular research are set out. Subsequently, the aim and objectives of the research as well as the research question, approach and methodology are outlined. There then follows a summary of the research contributions. The final section concludes the chapter with a brief overview of the thesis structure.

1.2 Research Context

Despite a growing recognition of the diversity of the older population, community living policies for older people and persons with disabilities are often designed in a fragmented manner with little collaboration or interaction between the ageing and disability sectors (Putnam, 2014). Furthermore, the interests of either group can be represented fleetingly or even be absent altogether in policy originating in the other sector (O'Donovan *et al.*, 2018). This is despite common challenges and the potential for common solutions. There are many possible explanations for this, including reluctance to position disability within paradigms such as 'successful ageing' (Rowe and Kahn, 1987) or reluctance to associate ageing rights with the disability rights movement for fear that disability will become synonymous with ageing. The converse is also true with hesitancy on the part of disability activists to be seen to suggest or support a conflation between disability and decline (Jönson and Larsson, 2009). There is also an apparent difference in the ways in which we view disability at different stages of the life course, with disability in younger people attracting significant attention with regard to issues such as employment, opportunity and social interaction (Putnam, 2011). Furthermore, though commonality of cause exists in ageing and disability sectors and organisations, representation of issues can differ with 'accessible housing' (disability) and 'housing for life' (ageing) being but one example (Priestley and Rabiee, 2002).

Older people and persons with disabilities desire to live independent lives in the community and be part of their communities (Löfqvist *et al.*, 2013; Dale *et al.*, 2012). Research supports rhetoric that the majority of older people, irrespective of disability status, want to remain living in their own homes, preferring to age in place (Fernandez-Carro, 2016, Ferris *et al.*, 2016, Sigurdardottir *et al.*, 2012, Wahl *et al.*, 2009). However, one's ability to live and age in the community is often contingent on having the necessary services and supports in place that facilitate continued community living. Persons with disabilities and older people can sometimes experience vulnerability in this respect (Breitenbach, 2001). Both groups may encounter similar challenges to retain autonomy and independence and their ability to live in the community may be stifled or suppressed through inadequate policies and a lack of community-based supports. Such shortcomings are likely to reduce the quality of life of older people and persons with disabilities in the community (Breitenbach, 2001) and expose them to a heightened risk of unnecessary institutionalisation (Ouellette-Kuntz *et al.*, 2017). Understanding what older people need in the community is important to support them to live in their own homes and prevent moves to institutions (Sigurdardottir *et al.*, 2012). Increasing the independence of persons with disabilities, including those who are older, benefits both the individual and society as a whole (Agree, 2014).

This research study is an exploratory study of the experiences of community living in Ireland for the group of people who occupy a space at the ageing/disability nexus. In interpreting the lived experiences of older persons with disabilities against the backdrop of the life course, this interdisciplinary research aims to address gaps in knowledge concerning the conceptualisation of community living for older persons with disabilities. Furthermore, it aims to bridge a policy gap by highlighting commonalities in ageing and disability that support the promotion, in policy, of holistic frameworks and approaches that offer better outcomes in terms of delivering meaningful community living across the life course. Such approaches reflect the call for consideration of the natural motion of life experience, whereby as needs change, so too would supports, irrespective of age and disability categorisations. Need rather than label and/or eligibility criterion would be the primary consideration in delivering meaningful community living policy responses.

1.3 Terminology

Words have meaning, evoke assumptions and carry connotations. It is therefore important that appropriate terminology is used when discussing older people and persons with disabilities. In ageing, terms such as ‘old’ and ‘elderly’ to denote older people are now rarely used and this reflects both the heterogeneity of the older population and more positive depictions of ageing and older age. Most importantly, it reflects the wishes of older people themselves (Quinlan and O'Neill, 2008, Falconer and O'Neill, 2007). In disability, terminology has also undergone change with stigmatising terms and labels that carried negative connotations having been replaced with more respectful, positive and affirming language (Friedman, 2017, Ford *et al.*, 2013).

However, it must be noted that within disability, there still exists differing terminology arising from different perspectives on disability. Terms used to describe people who have impairments differ with both ‘disabled people’ and ‘people with disabilities’ commonly used. The former is more often associated with, and utilised by, proponents of the social model of disability, and in the UK particularly (Lawson and Priestley, 2016). The latter is favoured by many disability campaigners outside of the UK, chosen for its positioning of people before disability. Furthermore, this is the language adopted by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). Motivated by a rights-based perspective and aligning with the view that the CRPD is a manifestation of the human rights model of disability, I have chosen to adopt this language.

Throughout this thesis the term ‘older persons with disabilities’ is used to describe older people who have physical, sensory, cognitive or intellectual impairments. This term denotes both people who have acquired their disability early in life (ageing with disability) and people who have acquired their disability in older age (ageing into disability). This terminology of ageing with and ageing into disability is in turn expanded upon in Chapter Two, as are the aforementioned models of disability considered in Chapter Three.

1.4 Positionality

Having an educational and professional background in law and legal practice, I pursued postgraduate studies in disability law and policy that nurtured a significant interest in issues of equality and social justice. I was therefore aware of the growing focus on rights issues both internationally and domestically for groups such as persons with disabilities and the consequential evolving policy landscape in social issues of relevance to such groups. My studies impressed upon me an appreciation of disability as a life-course phenomenon that knows no age boundaries and that can interact with other societal issues, such as community living and legal capacity.

I was particularly drawn to the convergence of ageing and disability in social issues such as long-term supports and the seeming scarcity of collaborative policy responses. This, coupled with my personal experience of family members ageing with disability, both lifelong and acquired, brought the issue of community living into sharper focus. I was naturally drawn to what community living means for those people who are experiencing disability in older age and, moreover, how this experience of community living could potentially be more meaningful. I was also interested in discovering how policy translates or maps onto lived experience. From this position, the idea for the research was conceived and progressed to a research study proposal that attracted funding, and received ethical approval.

I came to this research with my own personal views of what community living means stemming from personal experiences. Mindful of this, I was also aware of the need to contextualise those views within a broader evidence-based perspective. Capturing the lived experience of older persons with disabilities through a qualitative research study was therefore important. It was a means of ensuring that the perspectives of the people at the heart of the research would inform the research and challenge any preconceived notions, conscious or otherwise. Constructivist grounded theory was an approach that fitted with both this aim and my position as a researcher.

1.5 Aim and Objectives

The aim of this research is to better understand what community living means for older persons with disabilities, including those ageing with and ageing into disability, through an exploratory study of their experiences. The relative paucity of research focussing specifically on this group at the ageing/disability nexus (Jeppsson Grassman *et al.*, 2012) and on the topic of community living (Henning-Smith, 2017) provided the rationale for an exploratory study. Furthermore, by utilising the life course as an interpretive tool, it was intended that a more nuanced and in-depth understanding of community living for this group would be achieved, whereby account would be taken of shared and individual experiences, shaped and influenced by life-course factors. Indeed it is argued that disability in older age should be viewed in the totality of social locations in which it takes place, and past experiences, in order to better address needs that are fluid and interconnected (Grenier, 2005).

To achieve this aim, the research has three objectives: 1) to understand the constituent elements of community living; 2) to appreciate what community living means to older persons with disabilities (considering the influence of life course factors); and 3) to explore the perception of community living in the ageing and disability sectors (considering the silos and synergies that act as both rationale for, and create barriers against, greater alignment of ageing and disability in this policy area). These objectives were to be achieved and the aim of the research met through empirical research. Table 1.1 summarises the research aim and objectives.

Table 1.1: Research Aim and Objectives

Research Aim	To explore community living at the ageing/disability nexus	
Research Objective	**Method**	**Analysis**
To explore extant knowledge on the components of community living within a life-course framework	Literature review	Analytical literature review
To discover what community living means to older persons with disabilities	Interviews with older persons with disabilities living in the community	Constructivist Grounded Theory
To discover how community living is perceived in ageing and disability sectors and to better understand the silos and synergies that exist	Interviews with key expert ageing and disability stakeholders	Thematic Analysis

1.6 Research Question

The research question, *'how is community living conceptualised and experienced at the ageing/disability nexus?'* was born of a desire to better understand the lived experience of people who are both older and disabled. The characteristics and particular needs of people belonging to this group are not always addressed sufficiently by ageing or disability in either research or policy (Coyle and Mutchler, 2017). This arguably owes to the group's hybrid identity and straddling of both sectors. Furthermore, focus can tend to be limited to particular subgroups, such as older persons with intellectual disabilities (Bigby, 2002, Carling-Jenkins *et al.*, 2012, Kåhlin *et al.*, 2015b, Coyle *et al.*, 2016, Coyle *et al.*, 2014). Moving beyond this, I wanted to capture the rich diversity of this group, being people ageing with and people ageing into disability. I sought to understand what community living meant to this group and what they viewed as desirable or necessary in order to live and maintain meaningful lives in the community, on their own terms.

Having an awareness of the different opportunities and challenges that can present for older persons with disabilities, often linked to timing of disability onset, I was also keen to explore the influence of the life course. In this respect, the life-course perspective offered an interpretive lens through which community living for this group could be explored at the intersection of life pathways, developmental trajectories and social change (Elder *et al.*, 2003). Focusing on the relationship between the life course and community living, I wanted to explore in particular the extent to which life-course factors (such as social relations and resources) have a bearing on the conceptualisation and experience of community living in older age. Timing of disability onset can impact significantly on the resources and supports available to older persons with disabilities. Delving into the subjective experience of community living naturally afforded an account of the influence of such factors.

The research question also extended to stakeholders, as I wanted not only to understand the context in which older persons with disabilities experience community living, but also to expound why policy making, both nationally and internationally, in this area appears fragmented. As a result, stakeholders involved in advocacy, policy and services in both ageing and disability contexts at a national and international level were included in the study. Participating stakeholders were also able to address the ancillary issues relating to life-course factors. I believed strongly in the inclusion of a stakeholder perspective as understanding and potential change can only occur if a broad spectrum of relevant views is appreciated. In approaching key stakeholders from a variety of backgrounds, both in Ireland and internationally, it was possible to bring to the research study a dimension of ‘on the ground’ experience that would not otherwise have been achieved. Furthermore, the stakeholders selected for the study were of a high level that ensured a vital depth to the study owing to their breadth of expertise and grasp of the issues.

1.7 Research Approach

This research study adopts a social constructionist approach within the context of the life course. It is influenced by the position that life-course trajectories impact on later life experiences. In this way, the experience in older age of a particular social phenomenon is not viewed in a vacuum but rather in the context of the other influences that have featured over the life course. The group occupying this space are older persons with disabilities, a diverse group encompassing both people ageing with and people ageing into disability. This group is further diversified not least according to gender, place of residence, marital status and socioeconomic status. Within the context of the life course, this diversity was explored in greater detail as such social locations are relevant for their impact on issues such as resources and supports in later life, which in turn have a bearing on how community living is achieved, experienced and maintained. This approach accounts for variance in experiences owing to individual resources and positions (Jeppsson Grassman *et al.*, 2012).

1.8 Methodology and Methods

Despite their growing numbers, older persons with disabilities remain a relatively underexplored population group (Verbrugge, 2016). Moreover, where research has been conducted, it has tended to focus on sub-groups such as older people with intellectual disabilities, as aforementioned, with a particular emphasis on the ageing with disability category (Coyle and Mutchler, 2017, Clarke and Latham, 2014, Freedman, 2014, Iezzoni, 2014). As the aim of the research was to conceptualise the experience of community living for older people with disabilities within a broader life-course framework, I viewed an empirical study adopting a qualitative design as being the most appropriate to meeting this aim. Qualitative research allows the researcher to delve deeply into the world of the research participants and elicit their subjective understandings of the social phenomenon being studied. It is a personal endeavour whereby the researcher enters the world of the participants, who reveal what is inside them (Patton, 2015). This approach sat well with my epistemological and ontological position. As a researcher with a theoretical and practical background in law, the idea of combining that rationality with an exploratory study was appealing.

The empirical study adopted a two-phase approach. Phase One consisted of interviews with older persons with disabilities who were living in the community. Phase Two consisted of interviews with ageing and disability stakeholders. The two phases had the respective objectives of capturing voice and attaining insight, both adding to the overall understanding of what community living means at the ageing/disability nexus. For this reason, Phase One was very much an exploratory study and followed a constructivist grounded theory methodology for data collection and data analysis. Phase Two data employed the data analysis methodology of thematic analysis. These approaches corresponding to the research objectives are outlined in Table 1.1, 'Research Aim and Objectives' in Section 1.5 of this chapter.

1.9 Contributions

In line with the aim and objectives there are a number of contributions that this thesis broadly seeks to make. This study seeks to make a theoretical contribution by adding to what is already known about people who are occupying space at the ageing/disability nexus. By exploring how community living is conceptualised by people in this group, the research will also add to knowledge about the components of meaningful community living. It expands on the influence of life-course factors on the experience of community living in older age for persons with disabilities. Furthermore, this research applies a unique perspective on these issues in the Irish context. Methodologically, this study makes contributions to the utilisation of a constructivist grounded theory approach in conducting research with persons with disabilities, including intellectual disabilities.

From a policy perspective, this research also seeks to make a positive contribution in how the needs of older persons with disabilities are addressed.

Given the changing demographic characteristics of older persons with disabilities, addressing their needs through more comprehensive and encompassing policy responses will be an increasing priority. There is an increasing focus on rights for both persons with disabilities and older people, as evidenced by the CRPD and the work of the Open-Ended Working Group on Ageing (Leonardi *et al.*, 2012). There are also significant efforts to understand challenges, such as social exclusion (Dahlberg and McKee, 2018, Walsh *et al.*, 2017) and ageism (Larsson and Jönson, 2018), and to develop more inclusive communities through initiatives, such as the Age-Friendly Cities and Communities programme (World Health Organization, 2007) and research in this area (Buffel, 2018, McDonald *et al.*, 2018).

Inherent in these initiatives is a desire to deliver better outcomes for people who are ageing with disabilities and part of this is ensuring that policy responses are properly addressing needs. Community living is one such area of social policy and has significance for both ageing and disability. Heller (2019) emphasises that the goal of research and policy concerning ageing and disability should be the betterment of the lives of persons with disabilities. By incorporating into this research the perspective of ageing and disability stakeholders, efforts in this regard are augmented. This research adds to bridging efforts in ageing and disability and lends support to the supposition that greater alignment of policy between these sectors would be of mutual benefit.

1.10 Thesis Overview

The remainder of the thesis is divided into six chapters. In Chapter Two, the literature considered relevant to the study of community living for older persons with disabilities is reviewed. This has the purpose of positioning the research within the context of existing knowledge on older persons with disabilities in the particular realm of community living. Literature has been drawn from a variety of sources and from diverse disciplines, including environmental gerontology and disability studies. As this was an exploratory study adopting a constructivist grounded theory approach, the literature was expanded upon in parallel to the emergence of themes from the data. This chapter explores the ageing/disability nexus and the life-course framework. It moves on to a review of literature pertaining to the essential components of meaningful community living as generated through analysis of the empirical study data. These topics are home and environment, support, independence, resilience and social interaction.

Chapter Three considers community living policy in Ireland for older persons with disabilities. It presents an overview of ageing and disability policy developments in both the international and national context. The peculiarity of the Irish welfare state is considered. Illustrative policy examples are used to highlight shifting directions in both the ageing and disability sectors. The extent to which these shifts are impacting on the experience of community living is explored. Reform measures currently undertaken in the areas of deinstitutionalisation, home care and personalisation, are also considered in this chapter.

Chapter Four sets out the study methodology, research design and research methods as well as ethical considerations. This chapter provides a rationale for the chosen methodology as well as the two-phase approach that was adopted in relation to the empirical study. In this chapter, the particular issues associated with conducting research with groups often deemed 'vulnerable' are addressed, with consent and distress being particularly pertinent considerations.

Chapters Five and Six present the findings from the community-based interviews with older persons with disabilities and stakeholders respectively. Chapter Five follows an approach whereby for each of the five themes to emerge from the data, one participant has been chosen as a case study through which the particular theme is explored in depth with the utilisation of illustrative extracts from the data. Following on from this 'vertical' form of analysis, 'horizontal' data analysis is presented across the study sample under a number of headings. Chapter Six sets out the themes to emerge from analysis of the stakeholder interviews. It expands upon each of the three themes through subthemes, again with the aid of illustrative extracts from the data.

Chapter Seven is the discussion and conclusion chapter wherein I address what I hold to be the most significant study findings in light of the literature and the aim of the research, which was to explore community living at the ageing/disability nexus. It also offers a reflective view of the study and considers potential avenues for further research. This chapter culminates by drawing final conclusions on the research.

1.11 Chapter Summary

This chapter has served to introduce the research which focuses on the key research question, 'how is community living conceptualised and experienced at the ageing/disability nexus? It has also set out my motivations for carrying out this specific research study. It has outlined the methodology and methods that have been chosen as well as the rationale for their choice. Finally, it has given a brief overview of the structure of the thesis and what may be expected in the remaining chapters. The next chapter seeks to contextualise the research by reviewing literature pertaining to community living, ageing and disability and the life course. This literature is expansive and a research study of this nature would never claim to capture all the many dimensions and nuances of these topics. Furthermore, although literature contained in the following chapter has been chosen to provide background to the research topic, it stems predominantly from the research findings, as is to be expected in a study that draws upon the grounded theory approach.

Chapter Two

Conceptual Framework: Ageing, Disability, Community Living and the Life Course

2.1 Introduction

Although by no means synonymous, ageing and disability are intrinsically linked with commonality of purpose and experience characterising this nexus (McDaid *et al.*, 2009). Long set apart in research, policy and practice (Freedman, 2014, Putnam, 2014), the two phenomena have been characterised by differences of ideology, terminology and approach (Heller, 2019, Nalder *et al.*, 2017) and this has served to create silos in policies and service provision (Nalder *et al.*, 2017, Rickli, 2016, Wark, 2015, Putnam, 2011, Jönson and Larsson, 2009). For the most part, ageing and disability have remained distinct with relatively little effort to bridge the nexus between them (McGrath *et al.*, 2016, Heller *et al.*, 2015, Raymond and Grenier, 2013, Salvador-Carulla *et al.*, 2012, Kennedy, 2000).

However, there is a growing awareness and appreciation of both the advantage of adopting an interdisciplinary approach in ageing and disability research and policy, as well as the imperative to do so (Heller, 2019). This is particularly applicable in light of demographic ageing (Komp and Johansson, 2015b), increasing numbers of older persons with disabilities (Naue and Kroll, 2010) and evolving family formations (Henning-Smith, 2017). Demographic change necessitates joined-up thinking in order to produce policy responses that adequately address the needs of older persons with disabilities (Naue and Kroll, 2010). Furthermore, an interdisciplinary approach is useful when confronting issues that straddle sectors and impact on the lives of people who belong simultaneously to a number of different societal groups.

Community living is one such cross-sectorial issue. As an area of policy it exerts considerable influence on the way older people and persons with disabilities live and age in their communities. Although most older people live independently, some require support to remain living in the community (Murphy *et al.*, 2015).

The increasing number of older persons with disabilities, coupled with their desire to remain living in the community, make this an on-going policy issue (Craftman *et al.*, 2018, Paraponaris *et al.*, 2012). Irish policy, paralleling that of most other western welfare states, formally adopts the position that older people will be supported to remain in their own homes, with the necessary supports to facilitate this (Dempsey *et al.*, 2016) This is important as, by its very nature, community living is about being part of the community, however tenuous those community ties may be. While this is significant for all members of society, for people experiencing particular challenges or requiring additional support, it can become a more pertinent issue (Bigby, 2008). However, for older persons with disabilities, this is a policy issue that is fraught with inequities and inconsistencies. These arise not least from age categorisations and service demarcations (Nalder *et al.*, 2017, Ellison *et al.*, 2011), which will be explored in more detail in Chapter 3.

Distilled within ageing and disability, older persons with disabilities represent a group for whom such challenges can be nuanced and further impacted by factors stemming from their life-course experiences within both ageing and disability (Kelley-Moore *et al.*, 2006). They are subject to differing policy agendas in ageing and disability that impact on their ability to experience community living (Bigby, 2008). Community living is, therefore, a multidimensional issue for this group, warranting attention as an area of interdisciplinary research. This chapter considers the concept of community living in relation to older persons with disabilities within the context of the life course. This is a useful framework that recognises the increasing heterogeneity in research as well as the interplay between individual life trajectories and structural arrangements (O'Rand, 1996). Naidoo *et al.* (2012) credit the life-course perspective as a lens that recognises the differing experiences of people ageing with and ageing into disability. Therefore, exploring the intersection of ageing and disability against the backdrop of the life course helps to contextualise the research. It allows for a better understanding of the particular characteristics and experiences of older persons with disabilities by recognising their heterogeneity as a group.

The focus of this chapter is threefold. Firstly, ageing and disability are explored from both their individual perspectives and the commonalities that underpin the need to adopt an interdisciplinary approach in research and policy. Secondly, the concept of community living is considered, emphasising its constituent elements within the understanding of the concept as applied in this research. Thirdly, the influence and impact of the life course is explored with regard to the lived experiences of older persons with disabilities.

2.2 Ageing and Disability

2.2.1 The Ageing/Disability Nexus

Disability has always had an association with older age, most often in a negative sense of conflation between disability, impairment and age (Grenier *et al.*, 2016). Indeed, disability in older age has traditionally been normalised as part of the ageing process (Kelley-Moore, 2010). However, changing demographics and advancements in health and social care amongst other factors are bringing the ageing/disability nexus into sharper focus (Henning-Smith, 2017). More attention is being given to the diversity of both ageing and disability populations and their intersection, which has implications for both research priorities and policy design (Raymond and Lacroix, 2016). There is a growing interest in exploring the people who are living at this ageing/disability intersection, their unique experiences and how best policy may meet their needs (Leahy, 2018).

With increasing longevity, there is a natural associated rise in disability prevalence amongst the older population (Kingston *et al.*, 2018b, Kingston *et al.*, 2017, Connolly *et al.*, 2017) and this is forecast to continue (Kingston *et al.*, 2018a). These forecasts have far-reaching implications, particularly for policy responses, community care services and informal carers, who support older people with disabilities to remain living in the community (Jagger *et al.*, 2016). Additionally, people with life-long or earlier onset disabilities are now entering older age in increasing numbers (Coyle and Mutchler, 2017) and, in many ways, this is a relatively new phenomenon (Jeppsson Grassman *et al.*, 2012). This dual incidence brings ageing and disability together with opportunity for greater collaboration and alignment in research, policy and practice, with potential benefits for both sectors (Molton and Ordway, 2019; Leonardi *et al.*, 2012).

The group of people that may be said to straddle ageing and disability consists of people who are ageing with disability as well as people who are ageing into disability. As the general population continues to experience increased longevity, disability is more likely to feature in older age (Kingston *et al.*, 2018a, Freedman *et al.*, 2016). This may be termed disability with ageing (Verbrugge and Yang, 2002) or ageing into disability. Parallel to this, people who have experienced life-long or early-onset disability are now increasingly living into older age, owing in part to improvements in medical treatments and social conditions (LaPlante, 2014). This group are said to be ageing with disability (Verbrugge and Yang, 2002, Putnam, 2017) and are increasing significantly in number (Coyle and Mutchler, 2017, Molton and Yorkston, 2016, Freedman, 2014).

Although collectively people at the ageing/disability nexus may be referred to as older persons with disabilities, they are not a homogenous group (Jeppsson Grassman *et al.,* 2012), just as the ageing population itself is not a homogenous group (Biggs and Daatland, 2004, Arber and Evandrou, 1993), having been shaped by their diverse life courses and experiences (Gunnarsson, 2009) and the experiences, transitions and turning points over their life course will have an impact on how they come to experience community living in older age. They may face similar challenges but in other respects are quite different (Kelley-Moore, 2010). Furthermore, diverse life-course factors must be borne in mind when designing and implementing policies aimed at supporting community living. While these life-course factors and trajectories will be expanded upon in due course, it is necessary to begin by delving deeper into the characteristics of older persons with disabilities in order to understand their significance as a group in both research and policy design.

2.2.2 Ageing with Disability

In tandem with increasing age of the general population, we are also witnessing increasing numbers of people with disabilities who are living into older age (Raymond and Lacroix, 2016). This includes a rise in the average life expectancy of persons with intellectual disability (Bigby, 2008, Doody *et al.*, 2013). This is not altogether surprising when we consider advances in medical treatments and health care and an overall improvement in general living conditions. People who are ageing with a disability will have experienced disability from birth or from earlier in life. This group includes people with intellectual disabilities and with conditions such as spina bifida and cerebral palsy and could also include, for instance, people who have acquired brain injuries or spinal injuries (LaPlante, 2014).

Navigating social relationships, institutional structures, and the built and social environment can present varying degrees of challenge for people who are ageing with disability. As a result, disability becomes a significant aspect of both identity and daily life. This perhaps also is due to a stronger association with disability organisations and longer interaction with disability services over the course of a life lived with disability (Kåhlin *et al.*, 2015b). Ageing represents a new frontier for this group. An Australian study involving in-depth interviews with older people ageing with long-term physical impairments found that participants did not wish to be subsumed into the ageing category owing to their perception that their social roles and independence would be threatened by aged care services. Significantly, these participants identified as disabled rather than as aged and, while managing their conditions, they did worry about their ability to conform to the goal of ageing positively (Cooper and Bigby, 2014).

For people who are ageing with disability, it can be more difficult to differentiate between age-related changes and their disability, and in some cases having a disability can accelerate the ageing process (Ellison *et al.*, 2011**).** This is also seen in the association between certain conditions, such as Down syndrome and earlier onset dementia (Bigby, 2008). This acceleration can have consequences for independence as persons ageing with disability can experience the effects of ageing sooner and perhaps more significantly than people without disabilities and they may have fewer financial and personal resources to facilitate choice and thereby mitigate the impact of ageing (Ellison *et al.*, 2011). In this way, life-course factors influence the experience of ageing for persons ageing with disability, resulting in experiences that may be different for people who first experience disability as an older person.

People who are ageing with disability present both challenges and opportunities for the ageing sector, and therefore merit further research. Challenge lies in understanding and addressing the particular needs of older people with a life history of disability. Persons ageing with lifelong impairments can find their experience of older age frustrated and complicated by the lack of professional information to adequately address their concerns about ageing (Cooper and Bigby, 2014). Opportunity is found in a deeper understanding of the diversity of the older population and designing polices that are more inclusive and reflective of this diversity.

Ageing with disability is more often primarily associated with people who have life-long conditions. As a result, research on this topic has tended to focus on children and younger adults and often in relation to specific conditions, such as intellectual disability (Verbrugge *et al.*, 2017). However, disability may be acquired at any age and people who first experience disability in mid-life are also ageing with disability. Efforts to broaden this perspective to capture all ages have been made and have been furthered by developments such as the Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability (Verbrugge *et al.*, 2017). The authors of this declaration sought common ground and highlighted that although the experience of ageing with disability and ageing into disability may differ, the life-course trajectories were similar in terms of challenges and opportunities. The authors identified priority areas for bridging, including inclusion, participation and community (Bickenbach *et al.*, 2012).

Accordingly, the Toronto Declaration may be construed as a call for stakeholder collaboration by highlighting the benefits of focusing on commonalities of experience in services, supports and policies (Spindel *et al.*, 2012). The Graz Declaration on Disability and Ageing preceded the Toronto Declaration in 2006, and was spearheaded by ageing and disability stakeholders and NGOs. It adopted a human rights approach and focused on commonalities in ageing and disability and the special situation of older persons with disabilities, both lifelong and acquired in later life (Weber and Wolfmayr, 2006). Such broadening of the catchment of older persons with disabilities better reflects the diversity of this group.

2.2.3 Ageing into Disability

People who are ageing into disability may be categorised as people who come to experience disability for the first time in older age (Verbrugge and Yang, 2002). This may occur as a result of an illness, accident, impairment or condition. It is by no means a foregone conclusion that older people will age into disability and indeed many older people will live disability-free lives (Freedman *et al.*, 2016). Nonetheless, most disability in older age is acquired as a result of accident or chronic illness (Ferrucci *et al.*, 1996) and the likelihood of disability increases with age (Darling and Heckert, 2010). As the older population grows in number, there will be an associated rise in the number of people who will age into disability and continue to live in the community (Sugarhood *et al.*, 2017). Recent research (Kingston *et al.*, 2017) highlights that older men and older women will spend 2·4 and 3 years respectively with substantial care needs and that most will continue to live in the community.

The 2016 Irish census revealed 61,756 persons with disabilities aged 65 and over, with their disabilities relating primarily to chronic illness (e.g. heart disease) rather than to conditions that limit physical activities (e.g. arthritis). Most people aged 80 and over had a disability; 60% at age 85, rising to 90% at age 93 (National Disability Authority, 2018). Research conducted by Kingston *et al.*

(2018a) estimating future care needs of the older population in England predicts that while independence will increase for people aged 65 and over, increases will also be seen in the number of older people with complex care needs owing to the fact that more people will reach older age with higher levels of dependency and comorbidity and conditions such as dementia. This increase in care needs reflects population ageing rather than an increase in disability prevalence (Guzman-Castillo *et al.*, 2017). This is reflected in the 2016 Irish census, where the increase in the number of older people also saw a corresponding increase in the number aged over 65 with a disability (www.cso.ie/en/releasesandpublications).

People who are ageing into disability are markedly different from people who are ageing with disability. Although they may experience many of the same challenges (Kelley-Moore, 2010) and be similarly advantaged or disadvantaged by policies, their different pathways into disability and older age will have an impact on their experiences. People ageing into disability are more likely to have married, had children, been in paid employment and otherwise met the traditional markers of the institutionalised life course (Kohli, 2007). They will be shaped by these experiences and carry them into older age, thereby influencing and changing their experiences of disability in older age, as well as their preferences and expectations. Having located themselves within the aforementioned domains, persons ageing into disability are less orientated towards a disability-rooted sense of identity (Kelley-Moore *et al.*, 2006). Raymond and Lacroix (2016) highlight that there is significant work to be done to ensure disability in older age is viewed more positively with the goal of inclusion and participation of older persons with disabilities in society.

Differences of perception also exist when considering ageing into disability. For people belonging to this group, without a life history of disability, recognition of their disability is not assured and may otherwise be explained or justified as a consequence of ageing. This has been highlighted as a paradox in ageing and disability, whereby set apart for most of the life course they become conflated in older age (Grenier *et al.*, 2016). This exists not only in individual and societal perception, but is also reflected in institutional perception with chronological cut-off points for services and supports. This may be contrasted with the experience of people who are ageing with disability, who are more readily identified as having a disability and, accordingly, likely to have their experience acknowledged. Explanation may be found in considering how disability in younger age is viewed as non-normative and something that should not be a part of a person's typical, expected or 'normal' life course.

However, in older age, age and impairment become conflated as something to be expected at that stage of the life course (Grenier *et al.*, 2016). A person who becomes impaired in younger age and experiences disability is recognised as a person with a disability and as a person ageing with a disability. A person who becomes impaired for the first time in older age and experiences disability is not typically acknowledged as a person with a disability in the same way as a younger person. It is almost as if age legitimises the experience of disability. Indeed, impairment in older age is normalised with each advancing year. This is supported by findings from a US study, which explored perceptions of dignity and independence. Study participants linked declining capabilities with negative assumptions about their intelligence and condescension whereby decline was assumed "because your hair is gray and you have some wrinkles" (Black *et al.*, 2015).

Furthermore, the terminology associated with people ageing into disability is usually impairment rather than disability (Grenier *et al.*, 2016). This has consequences both for how persons ageing into disability view themselves and also how they are viewed by society. A consequence of this conflation is certain reluctance for persons ageing into disability to identify themselves as having a disability. Disability is more likely construed as an "add-on" and while it may significantly influence quality of life, it is not deemed sufficient to influence the core identity of the person from older to disabled (Breitenbach, 2001). Disability onset in older age has negative connotations and is frequently couched in terms of impairment, frailty, decline and burden. Indeed, loss is most often associated with disability in older age – loss of autonomy, loss of capacity to take care of oneself and perhaps even loss of the familiar environment (Monahan and Wolf, 2014). This issue has been addressed in research relating to orientation towards disability over the life course (Darling and Heckert, 2010). For persons ageing into disability, issues such as stigma, familiarisation with the medical model and a lack of interaction with other persons with disabilities and disability activism were considered factors leading this group to identify outside of disability. On the other hand, younger persons with disabilities, in the online era, were found to be more likely to be familiar with the social model of disability, activism and disability pride. Darling and Heckert (2010) highlight the correlation between timing of disability onset and disability identity. Disability, first experienced in later life, is often attributed to health-related causes such as stroke or mobility impairments and, as such, there is less chance that a disability-rooted identity will develop (Kelley-Moore *et al.*, 2006).

Interpreting and responding to disability differently for different population groups has ramifications in terms of policy, services and supports. Policies that are designed to deliver supports and services to facilitate independence and community inclusion with a focus on younger people who fit the chronological criteria for disability do not take sufficient account of people who live outside these criteria. This marginalises the experiences of people who are ageing into disability and highlights the importance of capturing their experiences so that they may also be included in relevant policy measures (Murphy *et al.*, 2007).

2.2.4 Rationale for Interdisciplinary Approach

Although distinctions in ageing and disability have been well established and perpetuated by research, policy and practice, some researchers argue that the time has come to move away from differences and instead focus on similarities of experiences, policies, services and supports (Bickenbach *et al.*, 2012). Since ageing and disability are interlinked processes, exploring their commonalities may benefit both sectors (Bitner and Franz, 2017, Nalder *et al.*, 2017). Although a conceptual divide has long existed between the two sectors and they have traditionally been set apart by both researchers and policymakers (Iezzoni, 2014), there have nonetheless been calls for greater cooperation (see commentary on benefits of bridging including that of: Nalder *et al.*, 2017, Coyle and Mutchler, 2017, Putnam, 2014, Heller *et al.*, 2014, Iezzoni, 2014, Bickenbach *et al.*, 2012, Leonardi *et al.*, 2012). Challenges that both groups encounter and which can be perpetuated by wider societal views include stigmatisation, medicalisation and institutionalisation (Naue and Kroll, 2010). Bridging between ageing and disability could serve to address such challenges through development of polices to support community living and long-term care that meet the needs of people ageing with and ageing into disability (Bickenbach *et al.*, 2012).

Freedman (2014), highlighting gaps in the demography of ageing and disability, brought together particular issues identified by researchers concerning people ageing with disabilities, including how they differ from people ageing into disability, and highlighted the continued existence of knowledge gaps in this regard. Efforts to move forward the agenda of bridging ageing and disability can be seen in recent forums stimulating scientific discourse with a view to addressing research and policy gaps in recognition of the changing needs of both sectors (Putnam, 2014). Moreover, the interdisciplinary nature of the fields of ageing and disability have been recognised as strengths, and collaboration could be achieved by integration of their theoretical and evidential frameworks (Coyle and Mutchler, 2017). Greater alignment could establish a research agenda that better encompasses the issues of both sectors (Monahan and Wolf, 2014). Such collaboration would also be more reflective of a life-course approach and better encapsulate the nuanced nature of the ageing/disability nexus.

Efforts to bridge ageing and disability requires action on multiple platforms, including research agendas, policy design and service delivery, with the overarching aim to improve inclusion, efficiency, equity of care and support at both the individual and societal level (Bickenbach *et al.*, 2012). Commonalities of experience in ageing and disability provide persuasive arguments for greater cooperation between researchers, policy makers, advocates and representative organisations (Naue and Kroll, 2010). Older people and persons with disabilities can face similar challenges in maintaining independence and autonomy in the community (Priestley and Rabiee, 2002). They also have shared experience of exclusion and discrimination (Glasby, 2017). These experiences can be exacerbated for the group of people who are at the intersection of ageing and disability, making older persons with disabilities a significant group in terms of research and policy.

Responses to particular needs are increasingly called upon to reflect the non-siloed nature of diverse needs (Nesbitt and Johnson, 2019). The particular experience of older persons with disabilities gives credence to the pursuit of an interdisciplinary approach in policy areas such as community living (Putnam, 2014). It is an area where interests align and needs intersect when considering both people who have aged with disability and people who have aged into disability (Bitner and Franz, 2017). Services and supports to facilitate community living and issues of independence and inclusion are pertinent to this population group as a whole. Although the experience of community living will naturally be influenced by life-course factors and possibly by a stronger disability identity for people who have a longer experience of disability, the core desire to live and age independently in the community is shared by all people belonging to this group.

Pursuit of a common approach and a more holistic policy agenda concerning community living has potential merits. Arguably, disability-friendly and age-friendly communities have something in common in that they are potentially more universally inclusive and accessible. Lowen *et al.* (2015), in their research on age-friendly communities and access to services for older people, highlighted the imperative to accommodate the needs of the older population, including relevant accessible services. It has been argued that adopting policy agendas that serve all people across the life course to live and age well may benefit society as a whole (Yeh *et al.*, 2016, Leonardi *et al.*, 2012). A more integrated approach could see disability and ageing scholarship share much in terms of the strategies and philosophies that underpin interventions in each sector, progressing both sectors and improving lives (Heller *et al.*, 2014). A positive ageing experience is possible for persons with disabilities, but is hindered by the delineation of aged care and disability services that exists in many countries (Cooper and Bigby, 2014).

Research plays a vital role in interdisciplinary efforts as it provides the evidence base for a deeper understanding of the issues, which in turn can inform policy and practice. Examples of such interdisciplinary research endeavours include the COURAGE in Europe Project, which was motivated by a need to integrate international studies on disability and ageing. This project collected data on determinants of health and disability in an ageing population with tools for evaluating the role of built environment and social networks on health, disability, quality of life and well-being (Leonardi *et al.*, 2014). Other interdisciplinary research efforts have made cross-national comparisons relating to specific issues such as accommodation support policies for older persons with intellectual disabilities (Bigby, 2010).

Policy also plays a part in furthering interdisciplinary efforts, as initiatives that recognise the need to serve populations that share common interests can deliver better outcomes in a more efficient and holistic manner. This necessitates adopting a collaborative approach through interdepartmental or cross-sectorial responses from policy makers (Wilkinson, 2003) and a more holistic approach in policy implementation (Lid, 2014). An example of this in the Irish context is the recent interdepartmental government policy statement on ‘the Housing Options for our Ageing Population’ (Department of Housing, Planning and Local Government and Department of Health, 2019). Overall, policies aimed at supporting older persons, including those with disabilities, to remain living in the community and avoid institutional care must be grounded in a solid evidence base (Henning-Smith, 2017). While policies that seek to promote the inclusion and participation of older persons with disabilities have been welcomed, researchers have argued that the perspective of older persons with disabilities is key within any agenda for change (Raymond and Lacroix, 2016).

Advocates and representative organisations in ageing and disability also have a role to play in furthering interdisciplinary efforts (Putnam, 2014; Priestley and Rabiee, 2002). Both sectors have particular strengths and expertise in areas such as activism and lobbying and this shared knowledge and experience, if utilised, can further both sectors in achieving better results for their represented populations. Setting the research agenda in turn impacts on policy. Bickenbach (2014), in discussing universalising social policy, refers to the inevitability of impairment, as functional loss, disease, injury and ageing are among the shared phenomena of the human condition. This interpretation highlights the diversity of the human experience where neither disability nor ageing is a static phenomenon experienced in isolation. Rather, they are nuanced processes and therefore policy responses to issues experienced as part of these processes, such as community living, also warrant nuanced responses. Such responses may be better achieved by greater interaction between ageing and disability stakeholders. Verbrugge (2016) contends that, as disability can occur at any time, an-all ages perspective is required and research that has hitherto been narrow can in fact be integrated.

Coyle and Mutchler (2017) highlight that both the ageing and disability sectors have strengths in supporting people who may require both ageing and disability services but that there is a need for both sectors to be sufficiently informed about the other. Both sectors offer expertise that could be amalgamated in order to provide services to older persons with disabilities that are appropriate, accessible and cognisant of the unique needs of this group (Bigby, 2002). Integrating disability and ageing services would help to ensure that the experience of older age for persons with disabilities would be positive (LaPlante, 2014). Both groups may require cross-departmental services in the community that will assist with activities of daily life as well as participation in the community (Molton and Yorkston, 2016). There is a need to orientate services according to need rather than age or status population groups. This would better serve the interests of all people in achieving goals such as meaningful community living. Should a person require supports to live in the community at age 64, the nature of those supports do not change in the main on turning 65. Moving beyond an arbitrary chronological “turf boundary” though policy collaborations offers the opportunity for ageing and disability to work together on issues of importance to both younger and older persons with disabilities (Kennedy, 2000, p.123).

Such arguments for an interdisciplinary approach must be considered against the backdrop of barriers that exist to hinder this process. The influence and impact of life-course factors, the construction of ageing and disability, as well as resistance on the part of older persons and persons with disabilities, their representative organisations, policy makers and service providers are powerful factors. Many of these barriers have their roots in the siloed nature of ageing and disability policy.

2.3 Community Living

2.3.1 Introduction to Concept

Community living is an area of policy that impacts on both older people and persons with disabilities (Bitner and Franz, 2017), exemplifying the commonality of interest and experience that lends itself to an interdisciplinary approach. Community living goes to the heart of what it means to be an included and valued member of society. While this is important for people of all ages and abilities, policies that impact on the experience and maintenance of community living assume greater relevance and resonate more deeply for people who are navigating the complexities of older age with the added dimension of disability.

The advantages of living in the community and having access to mainstream community services and supports are well established (Felce, 2016). Familiar environments are conducive to strong informal social networks (Gardner, 2011) and research (Pynnönen *et al.*, 2012) has highlighted that social activity decreases the risk of institutionalisation for older people. For persons ageing with disability, living in the community can mean benefiting from natural support networks and familiar environments (McCausland *et al.*, 2016). For persons ageing into disability, living in the community can facilitate better negotiation of new realities of impairment and the experience of disability. For older persons with disabilities as a whole, living in the community and having the opportunity to be part of the community also promotes social interaction, with the potential to mitigate against the ill effects of loneliness, isolation and exclusion, which can oftentimes be precursors to entry into institutional care (Nicholson, 2012). This is important given that both ageing and disability are associated with lower levels of social participation and that the risk increases for those who are both older and disabled (Sugarhood *et al.*, 2017). Research involving qualitative interviews with older women with intellectual disabilities living in the community found that being in the community allowed them to access and maintain their social networks (White and Mackenzie, 2015).

For the purposes of this research, community living is construed as living arrangements outside of formal institutional settings. This interpretation corresponds with that of the European Network of Independent Living, which emphasises the support and participation in the community aspects of community living (European Network of Independent Living). The interpretation adopted in this research therefore excludes large congregated residential settings for persons with disabilities but does include shared group homes in the community. The reasoning behind inclusion of the latter is that group homes are often the living arrangements for persons with disabilities transitioning into community living (Fundamental Rights Agency, 2018). Furthermore, following the distinction of ‘at home’ and ‘in a home’, a home in the community, even where support is provided by staff, can be a person’s own home so long as it does not conform to institutional characteristics (Martens, 2018). The Irish policy review on congregated settings (Health Service Executive, 2011) defined such residential settings as living arrangements where ten or more people share a single living unit or where the living arrangements are campus-style. Group homes refer to the arrangement whereby people with intellectual disabilities live together in the community with the support of paid staff from a service (King *et* *al.*, 2017; Health Service Executive, 2011). Nursing homes were also excluded from the interpretation of community living owing to their institutional characteristics. Accordingly, community living, as construed in this research, means homes in the community, shared or otherwise.

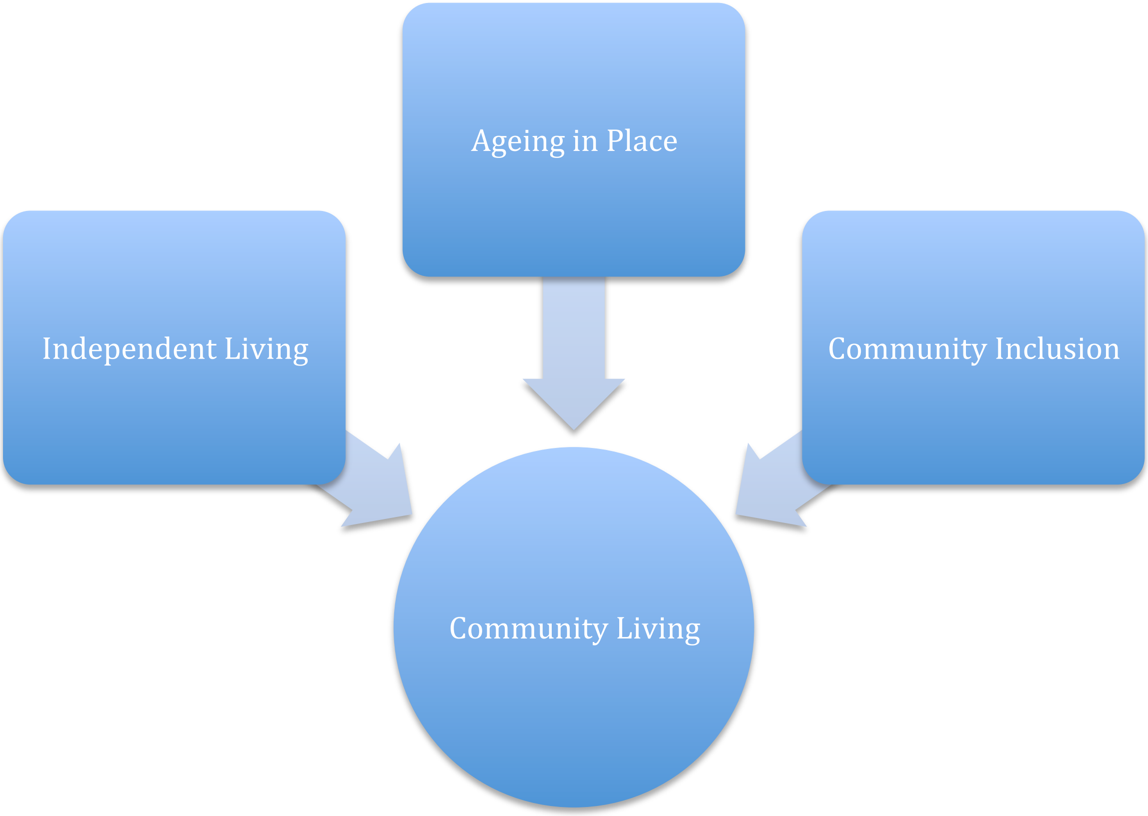
The understanding of community living in this research is also influenced and guided by the CRPD. The overarching guiding principles of equality and fairness are of central importance. More specifically, Article 19 on the right to live independently and be included in the community recognises the element of choice and control in where a person lives and the right to have access to appropriate supports and services, essential components of community inclusion. It is a seminal article and arguably one of the strongest in the CRPD as many other rights are contingent on being a part of the community. It is in the community that societal institutions such as education, housing, employment and services take place and persons with disabilities have a right to participate in these institutions (Owuor *et al.*, 2018).

The recent General Comment of the CRPD Committee (United Nations, 2017) succinctly captures the heart of Article 19 from a human rights perspective. The General Comment recaps the reality for persons with disabilities, long denied the right to make choices and have control over their place of residence and finding supports linked to particular living arrangements. Furthermore, resources have been invested in institutional settings rather than in the community with the consequences of dependency, isolation and segregation for persons with disabilities. In response to this reality, the General Comment highlights that the general principles of respect for the inherent dignity, autonomy and independence of the person as well as full and effective participation and inclusion are the basis to independent living and community inclusion. It is important to bear this assertion in mind when considering current policies for community living in Ireland. Older persons with disabilities, irrespective of timing of disability onset, can find recourse in Article 19.

2.3.2 Constituent Elements

Guided by the interpretation of community living adopted by the CRPD, the constituent elements of community living as applied in this research are independent living, ageing in place, and community inclusion, as depicted in Figure 2.1 below. Community living is interpreted in the context of older persons with disabilities as being the sum of these interlinked components. These elements are important for the realisation and maintenance of community living for older persons with disabilities, who may face particular challenges in this area. Furthermore, while there are differences of terminology and distinction of language within these concepts as applied in ageing and disability respectively, commonality is nonetheless present and rationalises the overall applicability of community living for older persons with disabilities (Priestley and Rabiee, 2002).

Figure 2.1: Constituent Elements of Community Living



2.3.3 Independent Living

Independent living is a central component of community living. It should not be erroneously construed as living alone or in total self-sufficiency. Indeed many older persons with disabilities will require some level of home-care services or supports in order to navigate the processes of daily life in the community and this need increases with variables such as living alone (Sandberg *et al.*, 2019). Independence in this context is therefore more about choice and control than self-reliance in the mechanics of daily living (Rabiee, 2013). Furthermore, it is likely that the level of support required will fluctuate depending on other factors such as periods of ill health and increasing age (Kåhlin *et al.*, 2015b). Many older persons themselves are also caregivers, providing informal support to spouses/partners and a wide range of family members, including ageing parents, adult children and grandchildren (Berridge, 2012, Di Gessa and Grundy, 2017).

This speaks to the interdependent nature of life in the community wherein support should be encouraged and provided when necessary. However, while it is recognised that assistance may be required in order to live independently in the community as an older person with a disability, the nature of the assistance must sometimes be called into question. In the Irish context, formal care is marked by unmet demand and an overreliance on informal care, predominantly delivered by female family members. The recipient of the support should be the director of the support, thereby facilitating continued independence and autonomy through choice and control rather than the passivity that has been the maker of traditional care in ageing and disability (Day *et al.*, 2018). This concept of self-directed support is inherent in the concept of independent living, as developed though activism in the disability rights movement (Evans, 2003).

Traditionally, services and supports were administered to persons with disabilities without much input from the individual service user or their advocates (Day *et al.*, 2018). Although change, particularly in the disability sector, is happening, other factors such as scarcity of resources and attitudinal barriers still exist to challenge the extent to which self-directed support is a reality. This may be attributable to prevailing resource systems. The traditional Irish approach to service provision, with a heavy reliance on informal support (Timonen *et al.*, 2012a), may be contrasted with the universalism that marks Nordic welfare regimes (Dahlberg *et al.*, 2018, Schön *et al.*, 2016, Haberkern and Szydlik, 2010). Independence for many older people is about making one's own decisions and exerting control in one's life, with this freedom enhanced and facilitated by remaining in the home (Haak *et al.*, 2007). Older people may be willing to accept home-support services to facilitate independence so long as they maintain control and autonomy with regard to the delivery of the services (Haak *et al.*, 2007). Consumer-directed care has been shown to reduce demand for residential care and to enhance quality, independence and well-being (Ottmann *et al.*, 2009, Glendinning *et al.*, 2008).

With increasing focus on issues of rights in both disability and ageing (Leonardi *et al.*, 2012, De Hert and Mantovani, 2011, Doron and Apter, 2010), independence and autonomy in service provision increasingly feature in independent living policies that impact on older persons with disabilities. Recognising that traditional approaches do not adequately address fluctuating needs, some countries, including Australia, Sweden and New Zealand, have introduced new approaches with more consumer direction and choice (Parsons *et al.*, 2018). However, Australian research into the experiences of older persons on the introduction of consumer-directed care highlights the associated challenges and the accompanying need for information and support (Day *et al.*, 2018).

As awareness of rights and less restrictive options have gained prominence, community-based supports have become more common. However, persons with disabilities and older people still face certain vulnerability in relation to living arrangements, which can be increased at the intersection of ageing and disability (Bitner and Franz, 2017). In Ireland, a significant proportion of older persons with disabilities live in institutional living arrangements. Approximately 2,579 people with disabilities, primarily intellectual, live in congregated settings, of which a significant number are older (Fundamental Rights Agency, 2017). Persons with disabilities, of all ages, live in nursing homes. However, amongst the population aged over 65, approximately 22,762 persons live in nursing homes (Census 2016). In nursing home settings, residents may experience loss of privacy, independence, autonomy, choice and control (Lee *et al.*, 2016). Nursing home care can become a reality for persons ageing into disability in situations where a lack of formal or informal support may make 'ageing in place' in one's own homes unsustainable. This is particularly the case in Ireland where a statutory right to home care does not yet exist but there is a right to support for residential care (Donnelly *et al.*, 2016, Timonen *et al.*, 2012a, Gannon and Davin, 2010).

Group homes are often employed as a community-based alternative to institutionalisation for persons with intellectual disabilities. Felce (2016) has highlighted that this reform has evolved over time in that group homes have tended to become progressively smaller. Greater autonomy (King *et al.*, 2017) and independence has been afforded to service users in choices regarding how they live, including in some cases personalised funding (Felce, 2016). One study, based on data from the first wave of IDS-TILDA, a longitudinal study researching ageing in Ireland among people aged 40 and over with an intellectual disability, found that people who were living independently or in community group homes had higher levels of ability in the performance of both ADLs and IADLs compared to those living in institutional settings (King *et al.*, 2017). This study's findings also revealed lower levels of ADL (Activities of Daily Living) and IADL (Instrumental Activities of Daily Living) performance amongst persons ageing with disability in residential settings. This highlights the importance of affording persons ageing with disability the opportunity to live in the community, reach their full potential and have a good quality of life.

An identified challenge to supporting persons with intellectual disabilities to live independently, identified as part of findings from an Australian study (Bigby *et al.*, 2017), is the availability of housing. Most study participants relied on social housing and indicated a preference for living alone. The issue of accessing housing compatible with need is also a significant consideration (Nesbitt and Johnson, 2019) and given housing shortages in general, can further hinder persons with disabilities in living independently in the community. This has been a contributing factor in the transitioning of persons with disabilities into community living in Ireland, as the current housing shortage has put considerable strain on the availability of suitable housing to meet demand (Salmon *et al.*, 2019).

Research in environmental gerontology emphasises the significant role of the home environment in older adults' daily lives (Wahl *et al.*, 2009). The home has been found to be a signifier of independence for older people, affording them a sense of control and confidence that they are managing their daily life at home, irrespective of functional decline (Haak et al, 2007). Sixsmith *et al.* (2014) conducted research on healthy ageing and the home with older people in five European countries. They found that older people viewed their ability to remain in their own homes, even if not the optimal environment, as an achievement over their own functional decline and frailty. Older people have been found to resist entry into residential care beyond what might seem possible, so strong can be the desire to remain living independently at home (Haak *et al.*, 2007). In this way, stages along the spectrum of independence to dependence have been identified that highlight the manner in which older people continually renegotiate their activities in order to adapt to changing circumstances including functional decline. Supporting older people to remain living independently in the community reduces the likelihood of avoidable hospital admissions and entry into residential care while also delivering a better quality of life (Grimmer *et al.*, 2015).

2.3.4 Ageing in Place

While independent living is commonly associated with disability studies, ageing in place is predominantly associated with social and environmental gerontology. However, for older persons with disabilities the two concepts are intrinsically linked. Ageing in place may be viewed as an effort to support older people to remain in the homes and communities of their choosing for as long as possible (Grimmer *et al.*, 2015). However, it is acknowledged that this ambiguous term couches a complex issue where change occurs and meaning and identity are renegotiated by the older person (Wiles *et al.*, 2011). Research on ageing in place is concerned with understanding the process of growing older in a familiar environment (Smith, 2009). In their discussion on environmental perspectives on ageing, Wahl and Oswald (2010) state that environmental gerontology supports an understanding of the relationship between ageing persons and their physical-social environments and how this influences different outcomes for older people with a goal of optimising this relationship. Ageing in place is contingent on community environments being appropriate places for the older person to age (Neville *et al.*, 2018). Environment is therefore a key concept in understanding ageing in place and, more particularly, the interplay between the person and the environment. A number of concepts are important in relation to the field of environmental gerontology and the study of ageing in place and are of particular significance in this research study.

The concepts of 'personal competence' and 'environmental press' were adopted by Lawton and Nahemow in the 1970s and remain significant in the field of environmental gerontology. Personal competences are linked to the person and may be internal (e.g. personality) or external (e.g. social networks) and exist along a continuum (Smith, 2009). Environmental press, which is also viewed along a continuum, considers how the person responds to the demands of their environment based on their competences (Smith, 2009). Ageing in place necessitates what is referred to as a person-environment fit (P-E fit). This may be described as the interaction between the older person and his/her environment whereby a match is sought between competence and environmental press (Lien *et al.*, 2015). Inherent in P-E fit is the fundamental assumption that for each person, an optimal balance exists that will result in their highest possible level of functioning (Wahl et al, 2009).

Wahl and Oswald (2010) propose a conceptual framework that accounts for two important constructs of P-E interchange in later life – belonging and agency, incorporating consideration of well-being, autonomy and identity. Wahl *et al.* (2012) contend that incorporating the processes of experience-driven belonging and behaviour-driven agency into the person-environment realm is beneficial for understanding the role of environment in ageing well. Incorporated into experience-driven belonging are both emotional and physical aspects related to such concepts as the meaning of home and place attachment and identity. Agency processes include relating to the environment through various adaptive, compensatory, sustaining and other behaviours. With their model, Wahl *et al.* (2012) posit that the processes of belonging and agency occur within a life-course framework, respectively increasing and decreasing in relevance or importance as a person ages.

Environment extends beyond the home and encapsulates the neighbourhood and wider community. Indeed, Verbrugge (2016) states that environment extends to social attitudes and social policies. As such, access to resources like community health facilities are important for well-being in older age (Oswald *et al.*, 2010). Older persons themselves acknowledge the importance of ageing in place in their own communities for the maintenance of their independence and autonomy (Black *et al.*, 2015). However, for older persons with disabilities, achieving this goal can be fraught with difficulties. Older age and disability can result in a heightened risk of institutionalisation, oftentimes owing to factors beyond an individual's control. A study involving interviews with 68 older adults aged 65 to 87 on the topic of why older people move out of their homes revealed five perceived advanced life events that impacted on the older person's ability to remain living independently: hospitalisation; falls/functional loss; dementia/cognitive loss; spousal illness or loss; and home upkeep issues. In exploring why participants felt they were unprepared for such events, rationales included perceiving a lack of options for adapting to changing circumstances and financial concerns about their ability to pay for their future support needs (Lindquist *et al.*, 2016). This study highlights the precarity that older persons, including people with disabilities, face when confronted with changing circumstances that threaten their ability to remain independent and age in place. Awareness and planning can work to mitigate the negative effects of such advanced life events and help ensure that older persons with disabilities can remain living in their own homes and age in place.

The home is of particular significance in the context of environment and ageing in place. It occupies an important place in the lives of older people as they spend a large proportion of their time at home. Aartsen *et al.* (2012, p.12) describe the home as “the quintessential expression of feeling comfortable, safe and welcome”. Home represents a place of both familiarity and comfort, and, when it corresponds to functional needs, can be a place of continuing independence (Cagney *et al.*, 2013). Undoubtedly, the home environment occupies a significant place in the lives of older people (Wahl *et al.*, 2009). For older persons with disabilities, particularly people who are ageing into disability, the extent to which the home may be deemed adequate for a person’s needs may become an issue warranting consideration. Persons who are ageing into disability may have lived in the same home for many years, but the new realities of impairment and disability may give rise to accessibility considerations and support needs that challenge the liveability of their home. In the absence of measures to counter this challenge, oftentimes unnecessary entry into institutional care is the outcome (Gibson *et al.*, 2012). In their review of research pertaining to the home environment and disability-related outcomes, Wahl *et al.* (2009) found evidence that improving the home environment reduces disability-related outcomes, but highlighted that the role of the environment should be considered in conjunction with the functional capacity of the individual.

Henning-Smith *et al.* (2018) have highlighted that older adults do not necessarily experience disability until an incompatibility arises between their home environment and their physical and cognitive abilities. A growing response to this issue is exploration of supportive technologies to facilitate independence and ageing in place. Indeed, environmental interventions such as home adaptations can be seen as facilitators of ageing in place (Van Hoof *et al.*, 2010, Lien *et al.*, 2015, Smith *et al.*, 2008). In her research on the living arrangements of community-dwelling older persons with disabilities, Henning Smith (2017), also highlighted that the home could be both a facilitator and a barrier to independence and well-being. Ageing in place with the necessary home supports is promoted as a strategy for maintaining the identity, autonomy and independence of older people (Van Hoof *et al.*, 2010). Research suggests that environmental interventions, such as home modifications, can reduce difficulties and increase safety for people ageing with disabilities in the community (Petersson *et al.*, 2008). Australian research on the housing preferences of older women experiencing multiple intersections of vulnerability found that housing suitable to need was a major consideration (Nesbitt, and Johnson, 2019). A high prevalence of age and disability amongst the respondents revealed accessibility, mobility and maintenance to be dominant themes, further highlighting the importance of the home environment to ageing in place.

In light of changing population demographics, the global rise in dementia and increasing disability prevalence in older age, smart technology is sometimes viewed as a means of relieving stress on aged care health and social support services (Morris *et al.*, 2013). A systematic review critical evaluation on the effectiveness of such technology to facilitate independent living and ageing in place found that there is merit and potential in this area (Morris *et al.*, 2013). However, it has also been highlighted that in the case of older people with dementia living in the community, people do not always receive the appropriate environmental interventions or modifications that would help facilitate them to age in place and support carers in this regard (Van Hoof *et al.*, 2010).

Lien and colleagues (2015) conducted a study of 12 participants aged 66-89 with one or more functional limitation in order to explore how they achieved a match between competence and environmental press. Their findings highlighted participants engaged in three adaptive environmental behaviours in order to achieve P-E fit. These were related to adjusting behaviours/attitudes, increasing functional/environmental support and counteracting losses in functional/environmental support (Lien *et al.*, 2015). Research on successful ageing at the intersection of various factors, including age and environment, found that, in addition to factors such as social embeddedness, congruence within the environment was also important for wellbeing (Mejía *et al.*, 2017).

The home is not just the physical rooms that a person occupies but also extends to the neighbourhood and to local services. Essentially, home refers to the "constellation of both the built and social community within which the individual resides" and there is a link between the length of time a person has resided in their home, the number and quality of meaningful relationships and social supports in the community and their sense of attachment to home (Stones and Gullifer, 2016). While older people can have a strong attachment to physical spaces, such as their home, garden and wider neighbourhood, they can also demonstrate a strong attachment to the people in the community. Indeed, familiarity of place and social connections are strong motivators for wanting to remain living in a place, even in times of changing circumstances (Even-Zohar, 2014). Moreover, close proximity to friends and services are important factors in facilitating older people's ability to age in place (Wiles *et al.*, 2011).

Research emphasises that there is potential to expand on the goodwill that already exists amongst neighbours and friends to support older people to remain in their own homes and that building on such community efforts would reap rewards and augment formal services (Black *et al.*, 2015). Community can manifest in different ways from neighbourhoods to networks to institutions that combine to shape the social environment in which older adults live (Cagney *et al.*, 2013). A study involving interviews with 80 German and Swedish participants aged 80-89 on the meaning of home found a strong attachment to home and a desire to age in place. Participants felt comfortable living in their neighbourhoods, having their social routines, and being in close proximity to family and friends. These factors motivated participants to strive to remain in their own homes. They felt that a move to a nursing home would represent deprivation of privacy, freedom, choice and autonomy (Löfqvist *et al.*, 2013). Research (Spoorenberg *et al.*, 2015) on experiences of older adults receiving integrated care, also found that a major fear was entry into nursing home care as this was seen as representing a loss of independence and control.

For older people, attachment to home, including possessions, memories and experiences, is well established (Stones and Gullifer, 2016). Home is therefore not merely a physical space, as aforementioned, but is also imbued with social and symbolic importance (Wiles *et al.*, 2011). Indeed, attachment to place has been shown to increase as people age and as they age the neighbourhood environment and its advantages and constraints become increasingly pertinent to wellbeing (Cagney *et al.*, 2013). Therefore, it is important to bear in mind the potential of the home environment to be both an enabling and a disabling space, depending on factors and circumstances (Gibson et al, 2012, Murphy *et al.*, 2009) and feelings of compromised independence can sometimes arise in the home (Hillcoat-Nallétamby, 2014). This is particularly relevant for older persons with disabilities, who may have fluctuating levels of support and who may find themselves confined to their home and excluded from the community. In such circumstances, the person may be ageing in place but at some cost to their wellbeing and overall quality of life. These circumstances present challenges that must be borne in mind when designing policies to support community living and ageing in place.

Wahl and colleagues (2012) contend that for all its potential to impose constraints in older age, the physical environment may also enhance possibilities for ageing well as assistive technologies and new housing models can compensate for declining competencies (Wahl *et al.*, 2012). Furthermore, they define ageing well as maintaining the highest level of well-being, autonomy and sense of self as possible, even when confronted with loss of competences (Wahl *et al.*, 2012). Arguably, with the requisite community supports and necessary home adaptations and assistance, older persons with disabilities may well stay in their own familiar home environments should they choose to do so, living and ageing well in the process. Indeed, recent Irish research revealed that in the event of the home becoming unsuitable, the first preference for 78% of the older people surveyed was to adapt their own home (Department of Housing, Planning and Local Government and Department of Health, 2019).

A New Zealand study exploring the meaning of ageing in place for older people revealed an overarching message that older people desired choice regarding their living arrangements and to have availability of services and supports (Wiles *et al.*, 2011). Furthermore, for many participants in this study, remaining in their own homes meant avoiding institutional care and preserving autonomy and independence. For some participants, family support and local resources in the community, such as transport services, facilitated these goals. Ageing in place may, therefore, be said to exist along a continuum with the potential to facilitate both independence and support. Ontario, through its 'Aging at Home Strategy', provides an example of such a continuum of support in the form of a commitment to community living for all older adults irrespective of disability status (Ouellette-Kuntz *et al.*, 2017).

Similarly to the aforementioned New Zealand findings, an Australian study exploring older persons' experiences, perspectives and strategies relating to ageing in place revealed personal characteristics of independence, resilience and adaptation. Participants in this study were determined to remain in their homes in the community, demonstrating resilience in the face of obstacles and a willingness to take proactive steps to adapt their activities and environment in order to achieve the goal of ageing in place (Grimmer *et al.*, 2015). Resilience in this sense may be understood as an adaptive process whereby older people respond to events and setbacks and adopt coping strategies to maximise independence (MacLeod *et al.*, 2016). Simple and relatively low cost interventions and supports were identified that would allow autonomy and independence to flourish while affording the older person an opportunity to adapt to their changing circumstances and needs. Overall, while participants were optimistic about remaining in the community, they highlighted the need for tailored as opposed to generic supports and reliable and flexible community-based services that put the person first. This was contrasted with a medicalised model of support that sees decline as a foregone conclusion and does not allow for the autonomy of the individual in support arrangements (Grimmer *et al.*, 2015).

Undoubtedly, independence and autonomy are key components of ageing in place, as shown in a recent study examining older people's perceptions of the ideal characteristics of a neighbourhood for ageing in place (Van Dijk *et al.*, 2015). This study found that older people evaluated these characteristics with regard to the extent to which they afforded them the opportunity to retain autonomy and independence in reference to both past experiences and future expectations This is supported by findings from a US study (Black *et al.*, 2015) exploring ageing with dignity and independence that highlighted the importance of ageing in place to this goal. Participants suggested that their dignity was hinged on self-reliance and self-sufficiency and on not being a burden to others. Furthermore, simple adaptations and interventions were reported to further these feelings of self-reliance and independence.

2.3.5 Community Inclusion

Being included in the life of the community is a central component of community living, and one that can be particularly difficult to maintain for older persons with disabilities. Age and disability can present their own unique challenges that sometimes limit the ability of older people and persons with disabilities to maintain social networks and integration in the community. Factors that impact on participation, inclusion and connectedness in the community include the loss of friends and family and inaccessible environments that impinge on mobility and limit opportunities to socially engage (Aubrecht and Krawchenko, 2016). For people who are both older and experiencing disability, these challenges can become exacerbated and, at times, insurmountable in the absence of adequate services and supports.

Social networks play a vital role in facilitating community inclusion for older persons with disabilities. Furthermore they are intrinsically linked to well-being and quality of life. In their study on perceptions of engagement in rural communities for older people, Neville *et al.* (2018) found that maintaining social networks, including those consisting of friends, was a major theme. These networks played a central role in support, interaction and ensuring respondents felt connected to their communities. Friendship networks especially were identified as contributing to older people's resilience.

The social networks of persons with disabilities are generally weaker than those of the general population (Duggan and Linehan, 2013). Evidence from the Irish Longitudinal Study on Ageing (TILDA) shows quality of life as being highest for those most integrated in social networks and lowest for those most isolated (Nolan *et al.*, 2014). As a result, social connectedness is a key consideration for persons ageing with disability (McCausland *et al.*, 2016). In a similar vein, Cornwell (2014) found that the network ties and support resources of community-living older people meant that they were less exposed to harmful living conditions. However, social networks can become depleted over time. As people age, social networks are subject to natural decline and with this comes an increased exposure to loneliness and social isolation. Indeed, older people's social networks may become compromised owing to myriad factors such as caregiving responsibilities, death and illness of family and friends or geographic factors (Black *et al.*, 2015). Work in the USA has explored the relationship between disability and loneliness among older married adults (Warner and Kelley-Moore, 2012). Within this context loneliness was shown to be a potential adverse outcome of disability where low levels of positive marital quality existed.

People ageing into disability may experience a decline in opportunities to be active in the community as impairment may reduce the feasibility of social interactions that would have previously been part of their routine. For persons ageing with disability, such opportunities may have been even scarcer as social networks may never have been all that diverse to begin with. Family members and professionals dominate the social networks of people with intellectual disabilities (Simplican *et al.*, 2015). People with intellectual disabilities are less likely to have formed relationships with people who do not also have an intellectual disability (White and Mackenzie, 2015). Clement and Bigby (2009) reflect that, for persons with intellectual disabilities, small and restricted social networks, consisting largely of family members, others with intellectual disabilities and paid support workers, tend to be the norm, although change has started to come about formulated on the concept of inclusion. Furthermore, although strongly linked to the importance of informal social networks, de-institutionalisation has not necessarily led to a broadening of social networks for persons with disabilities (Cummins and Lau, 2003).

Undoubtedly, living in the community and having the opportunity to be a part of the community is important for community inclusion. Routine tasks, such as shopping and socialising in community spaces and places, provide this opportunity. Having a presence and a vested interest in a community leads to a deeper connection to that community and the other inhabitants. Research conducted by the Fundamental Rights Agency (FRA, 2018) found that Irish service provider staff and managers linked activities, such as shopping locally, as being central to community inclusion for persons with disabilities living in the community. However, Clement and Bigby (2009) also highlight that community presence in and of itself does not automatically imply social inclusion. These are issues that arise for persons ageing with disability as community inclusion is tied to opportunity for engagement and interaction. Duggan and Linehan (2013) highlight the importance of community inclusion considerations in jurisdictions such as Ireland where disability services are being reconfigured to ensure that policy aims are being met. They point to the favourable outcomes associated with community connectors and community inclusion officers within disability organisations to enhance natural supports for persons with disabilities in order to promote independent living and community inclusion.

For older persons with disabilities, as a whole, community interaction is an important aspect of community living. Golden *et al.* (2009) have shown that social engagement through participation in social events and contact with friends and neighbours is effectively the manifestation of social support networks. As people are unique individuals, they will naturally require varying degrees of social interaction. Studies suggest that older people value informal social encounters more than those provided by social workers in designated activity centres. This highlights the need to be cognisant of what older people themselves want from community interactions (Singelenberg *et al.*, 2014). For some, casual encounters in the community with shop assistants and health professionals may be enough to satisfy their social requirements. May and Muir's (2015) study concerning belonging and ageing amongst participants aged over 50 found that such 'incidental encounters' could be significant to a person's sense of belonging in a place and, furthermore, that strong social ties were not necessarily required in order to feel content and comfortable in a place, when a general sense of friendliness prevailed (May and Muir, 2015). Others may relish more regular and deeper connections. However, regardless of the level of interaction, having the opportunity to engage in the community is important for overall well-being and connectedness.

2.3.6 Importance for Older Persons with Disabilities

Community living, under the guise of independent living or ageing in place, is an area of policy where ageing and disability share much commonality of purpose and experience. It also epitomises the re-imagining that is called for in social policy discourse when considering the supports that are required for independence and community inclusion. Indeed, persons with disabilities have long campaigned for this re-imagining, seeking not to be regarded as passive recipients of care but rather as active players with a say in how services and supports are designed and delivered. Care, perpetuating dependency and passivity, has been challenged (Kelly, 2017). Essentially, what has been sought is a "reconceptualization of the care/dependency dichotomy" (Fine and

Glendinning, 2005, p.610). There has been a challenge to oppressive, institutional and disempowering attitudes and practices (Douglas *et al.*, 2017). Although this demand may not echo as resoundingly in the ageing sector, there is nevertheless a growing awareness that the meaning and operationalisation of care and support in policy must be re-evaluated. To an extent, this re-evaluation is predicated by mounting discourse around human rights and the associated principles of autonomy, dignity and independence. Terms such as user-led and self-directed care are increasingly becoming part of the social care vernacular. This naturally translates into a need for innovation in the traditional care paradigm.

The desire to live in one's own home is of paramount importance to the vast majority of people irrespective of age (Lindquist *et al.*, 2016). Indeed, the overwhelming majority of older adults live in the community rather than in nursing homes (Oswald *et al.*, 2010) and this is the case in Ireland (Murphy *et al.*, 2015). Inherent in this is the desire to remain in familiar environments for as long as possible with continuity and control over central aspects of life (Wahl *et al.*, 2012). However, although this preference for community does not necessarily lessen with increasing age, the ability to maintain community living can be affected where disability is added to the equation. Although older persons with disabilities want to live in place, they may not have the appropriate living arrangements to facilitate this (Henning-Smith, 2017). Home and community based services are a means of avoiding institutionalisation and supporting the independent living and ageing in place preference of older persons with support needs (Ferris *et al.*, 2016, Ng *et al.*, 2015). In the absence of robust polices that support community living with adequate provision of community-based supports and services, community living for older persons with disabilities is harder to maintain and for some may be unattainable (Allen *et al.*, 2014).

Research suggests that informal support, particularly from adult children, is unlikely to keep pace with demand (Kingston *et al.*, 2018a). Furthermore, spousal carers are increasingly living with disabilities themselves (Department of Health, 2012). This impacts on the ability of both partners to remain in their homes and communities. Accordingly, as the number of older people increases and the availability of informal carers decreases, innovative polices that support older people to remain in the community are called for (Singelenberg *et al.*, 2014). This goes hand in hand with a need for innovative research to better understand and facilitate ageing in the community (Black *et al.*, 2015). At the heart of community living are the principles of independence, autonomy and inclusion. Policy initiatives and strategies set an agenda for how society responds to societal issues. Their support for the aforementioned principles can be strong, silent or ambivalent. Policies set the tone and provide a blueprint that translates into action. Services and supports, properly designed and delivered, can facilitate and enhance the experience of community living for all older persons with disabilities, with all their diversity of circumstances and needs.

Pursuing the goal of ensuring that all older persons with disabilities have the opportunity to live and age in homes of their choosing in the community means prioritising community over residential care. It means putting in place the building blocks for community living, which address the physical, social and psychological needs of older persons with disabilities. This entails ensuring that adequate resources are allocated to home support services and community health services. It also means ensuring that older persons with disabilities have the opportunity to be a part of their communities and continue to do so irrespective of fluctuating levels of need. Schön *et al.* (2016) highlight that most countries now base their long-term care policies for older people on the principle of ageing in place with a focus on community-based support and home adaptations as well as other assistive devices and support, which enable older persons with disabilities to live independently in the community. However, they also point out that as ageing in place becomes a reality for more and more older people, there is a need to explore the implications of this for both the older person and the long-term care system (Schön *et al.*, 2016).

2.4 The Life Course

The life course may be said to "capture the fluid and changing aspects of experience" (Grenier, 2012, p.8). As a concept, the idea of the life course has gained considerable traction in the field of ageing research and can be viewed as a valuable tool in the study of ageing and human development (Alwin, 2012). Viewing the life course as a theoretical orientation, it has been explained as consisting of "age-graded patterns that are embedded in social institutions and history" (Elder *et al.*, 2003, p.4). Within this context, pathways, trajectories and transitions are of relevance. Expanding upon these concepts, life pathways are described as the trajectories through society that are followed by both individuals and groups. The trajectories of roles and experiences are in turn marked by transitions, such as marriage or retirement, which may have lifelong implications. The life course offers a framework for studying issues at the intersection of life pathways, developmental trajectories and social change (Elder *et al.*, 2003).

The life course is, therefore, a useful backdrop from which to explore the experience of community living for older persons with disabilities. It serves as a lens through which the differing experiences of people ageing with and ageing into disability may be viewed (Naidoo *et al.*, 2012). Exploring the concept of disability in older age in this context implies considering the meaning of disability within the wider context of "life's dynamics" where temporality takes on different meanings (Jeppsson Grassman *et al.*, 2012, p.97). Heller (2019) describes ageing as a dynamic process whereby change is not only individual but also social and environmental. These changes must be considered in light of life-course factors that impact on how a meaningful older age may be achieved. Dannefer and Settersten (2010) note that the life-course perspective is valuable for its recognition that life experiences shape how people age and that these life experiences are formulated on social relationships and social contexts. Kohli (2007, p.256) refers to the life course as creating "life time continuity punctuated by collective transitions, in other words, some measure of life time security and predictability". As Hendricks (2012, p.231) states, "the experience of life is cumulative, continuous and never ending so in order to make sense of any given period, we need to consider whole lives in the contexts in which they unfold".

Within the particular social context of community living for older persons with disabilities, trajectories and the social roles that older persons with disabilities occupy are of relevance. So too are the opportunities and constraints that have presented at different stages of life and the impact of the timing of disability onset on these opportunities and constraints. This is linked to the role of the institutionalised life course, articulated though ageing/disability policy where dependency has been fostered to the detriment of independence. In her consideration of the intersectionality of age, disability and the life course, Kelley-Moore (2010) unpacks some of these issues in terms of social constructions and widely held perceptions. Exploring the heterogeneity of the older disabled population brings these issues into sharper focus.

2.4.1 Paradigms

Dannefer and Settersten (2010), in their discussion of the life course and social gerontology, allude to the explanatory paradigms of the personological and the institutional. The former paradigmatic approach operates on an individual level, whereby earlier life events are utilised as predictors for later life outcomes. The institutional approach, on the other hand, operates on a societal level, viewing the life course as a social construct with age-graded institutions, which are operationalised through institutions and policies. My research acknowledges both these paradigms in its contention that the experience of community living in older age for persons with disabilities is impacted by both individual life-course experiences and the institutionalised life course. Older persons with disabilities in this study are not a homogenous group and this is expected given that persons with disabilities overall are not a homogenous group (Jeppsson Grassman *et al.*, 2012). Accordingly, older persons with disabilities are marked by both their individual life course experiences and their interactions with societal structures, offering both choices and constraints. Indeed, characteristics of identity, apart from age or disability alone, intersect and interact to shape one's opportunities as well as capacity to withstand disadvantage arising from life's circumstances (Milligan and Thomas, 2016). Furthermore, nor does this group experience disability homogenously. It is to varying degrees impacted by social and environmental factors (Henning-Smith, 2017).

2.4.2 Trajectories

Morgan and Kunkel (2016) highlight that values, preferences and actions in later life are the result of the sum of individuals' experiences and social circumstances over their lifetime. Despite the individual nature of the life course, there is a "social timetable" of institutionalised norms (Jeppsson Grassman *et al.*, 2012, p.97) that is generally adhered to and serves as a navigational tool for life's journey. The life trajectories of older persons with disabilities vary according to a number of factors, not least the timing of disability onset. The timing of disability onset can affect the aforementioned social timetable of norms, with ripple effects still being felt in older age. Its impact on an individual's life trajectory may have relevance in education, employment, relationships and resources. These are all important contributing factors to the experience of community living and, in particular, independence and autonomy in older age.

Irrespective of the stage of the life course that disability is first experienced or the associated social and economic factors that impact on that experience, "these life course trajectories present similar challenges and opportunities" (Bickenbach *et al.*, 2012). Therefore, despite variance in trajectories, the commonalities of experience in ageing and disability are a unifying force in seeking policies that support independence and community inclusion. Inclusion Ireland (2017a) recently highlighted that, although the ageing population is diverse, independence, autonomy and inclusion are among the most important themes in both disability and ageing.

2.4.3 Influence of Life-course Factors

Ageing with Disability

For people who are ageing with disability, life's pathway will have been influenced to a large extent by the societal and institutional response to their disability and the individual opportunities or constrains that have led on from this. Timing of disability onset particularly impacts on services and supports. Persons with disabilities and their families are more often accustomed to negotiating social care pathways. Accordingly, this will have resonance in how they access services as an older person with a disability. By contrast, older people experiencing disability for the first time in older age may only engage with formal services when need suddenly arises. Individuals belonging to this group may be less experienced in accessing information and services (Putnam, 2011). Reliance on state support in matters such as income, housing and healthcare can see persons ageing with disability at a disadvantage relative to people who are ageing into disability. Health, economic status, employment and social backgrounds are all factors in this relative disadvantage (Clarke and Latham, 2014).

Reflecting the diversity of older persons with disabilities, people ageing with disability may, therefore, have unique needs and face particular barriers in seeking to age in the community (Coyle and Mutchler, 2017). They may be approaching older age from the perspective of already having a history of complex health and social situations as a result of disparity of treatment in relation to meeting their needs (Putnam, 2017). Bigby (2008) has highlighted that the disability-related needs of the person do not disappear with older age and, accordingly, aged services should complement rather than replace the supports in place to meet these needs. Persons ageing with disability run the risk of falling between the cracks as the ageing sector may not be prepared to address their particular needs and the disability sector may not be equipped to help them navigate older age (LaPlante, 2014).

As well as a rise in the proportion of persons ageing with physical impairments, persons with intellectual disabilities are also experiencing older age in increasing numbers (Coyle *et al.*, 2016). These developments necessitate addressing issues that will increasingly arise for this population group**.** Ireland has recently witnessed a significant increase in the number of persons with intellectual disabilities aged 55 and over. This group now represents 12.4% of the total number of persons with intellectual disabilities (Family Carers Ireland, 2015). Persons ageing with disability are differentiated from people who acquire impairment in older age owing to their particular life experiences (Cooper and Bigby, 2014). Accumulated inequality in the realm of health, wealth and social capital over the life course are significant factors for this group (Clarke and Latham, 2014) and difficulties experienced in older age may include impairment progression, ancillary impairment and insufficient opportunity to build resources (Cooper and Bigby, 2014). In linking ageing theory and disability models, Putnam (2002) highlights the variance in the ageing experience owing to timing of disability onset. Putnam considers the different life experiences that people ageing with disability will have had and how this will have influenced the ageing experience.

Persons ageing with disability may also face particular precarity in older age regarding issues such as housing, healthcare, pensions and insurance. Owing to life-course factors, such as limited educational or employment opportunities, some people may not have had the opportunity to accumulate financial resources to adequately provide for their needs in older age. Owing to attitudinal barriers amongst others, persons ageing with disability, may also have had limited opportunities to engage in social relationships and build up social capital to buffer the effects of disability in older age and the uncertainty that can arise when support networks naturally diminish. This has a significant bearing on community living in older age as in the absence of independent resources, adequate support and security of environment, persons ageing with disability risk institutionalisation and a loss of independence in the community (Ouellette-Kuntz *et al.*, 2017).

Ageing into Disability

Persons who are ageing into disability will also find that their experience of ageing, disability and issues such as community living will be impacted by their life trajectories, where disability has not been a factor in their choices and opportunities. Although persons ageing into disability may not have the same experience negotiating social care pathways, they are equipped with other experiences accumulated over the life course. They will come to older age having experienced different life-course events and transitions pertaining to the institutionalised life course, such as employment, housing, services and relationship formation and, possibly, dissolution. These experiences may be called upon to assist individuals in negotiating the complexities of disability experience in older age.

Having been in paid employment links to acquiring resources and entitlements associated with the status of an economic actor. Having lived independently, formed long-term relationships, and had children links to an increase in potential for informal support in older age. Together, this may result in people ageing into disability being less reliant on the state for meeting their support needs. However, persons ageing into disability may nonetheless face challenge and uncertainty that necessitate policy interventions. Although life-course trajectories may make transitions easier to predict, the reality is that disability and ageing are not stagnant phenomena (Heller, 2019).

Experiencing disability for the first time in older age is not free from challenges. Persons who are ageing into disability may find that they do not fit the typical profile of a person with a disability and may find their disability dismissed as an unavoidable or even expected consequence of the ageing process. This may require older persons with disabilities to be more assertive in their dealings with health and care professionals so that their concerns and symptoms are not dismissed as part of ‘normal’ ageing (Kelley-Moore, 2010). Nevertheless it must also be noted that research highlights that having children, having a strong social network and support to call upon makes older people with disabilities less likely to identify as disabled (Kelley-Moore *et al.*, 2006).

Chronological age distinctions with regard to eligibility for disability supports are also not uncommon (see, for example, countries such as Switzerland (Rickli, 2016)) and highlight the ambiguous position that may arise for some older persons ageing into disability. Owing to the later timing of disability onset, people in this group may be ineligible for certain benefits or supports. Curtailment of support in this manner may have the consequence of exacerbating individuals' experience of disability. Equally, such people may find that they do not conform to the image of a physically and socially active older person, successfully negotiating older age.

Commonality

Disability in later life is affected by experiences throughout the life course (Kingston *et al.*, 2015). As highlighted earlier in this chapter, older persons with disabilities represent a diverse group with identities largely influenced by life-course transitions. The timing of disability onset, severity and duration are important factors in considering how disability may impact at different life stages (Putnam, 2017). For people who are ageing with disability, either lifelong or acquired in younger or mid life, becoming an older person can almost serve to make their disability invisible. However, this belies the reality that there is no definitive point at which a person with a disability becomes an older person as their life experience as a person with a disability impacts on their interactions with supports and services in older age (Bigby, 2002). Although, in some cases, persons with disabilities may continue to receive supports and services from the disability sector, despite reaching the chronologically defined point of entry into older age, this is discretionary and anecdotal. Such ambiguity leads to uncertainty and unequal provision. This has many consequences for older persons with disabilities, including people with intellectual disabilities, where state policies in many countries lack clarity with regard to which sector services have responsibility for meeting their needs (Carling-Jenkins *et al.*, 2012).

Effectively, older persons with disabilities, depending on life-course factors, including timing of disability onset, may find themselves set apart from either the ageing or disability sector, and indeed neither may be an entirely comfortable fit. Their experiences at different stages of life and their opportunities to engage in social roles and develop social networks, build resources, as well as their interaction with the mechanisms of the institutionalised life course, all have a bearing on their experience of community living in older age.

2.4.4 Social Networks and Social Roles

Social roles are often assigned on the basis of age as a method of organising the social life of people. This leads to general views on age-related expectations for the life course (Morgan and Kunkel, 2016). Furthermore, the life course is "generally delineated by the roles we are expected to play in particular sequences or within particular age ranges" (Morgan and Kunkel, 2016, p.89). Through acquisition of positions and roles in social structures, the life course may be seen as embedding individual lives in the social structures that stem from the institutionalised life course (Mayer, 2004). Social networks and social contexts, in turn, influence the life course (Komp and Johansson, 2015b). Persons who are ageing with disability do not always conform to the socially choreographed ideal sequence of the life course. Social networks and social roles are intrinsically linked and are important to a person's sense of self. Kelley-Moore *et al.* (2006) highlighted the positive impact and benefits of social networks to one's perception of self as an independent and non-disabled older person. Social networks and social roles also serve to better position a person to deal with the fluctuation of life's experiences. However, age and disability both have an impact on social networks and roles. The social networks of persons ageing with disability are affected by the opportunities and constraints that have persisted throughout their life lived with the experience of disability.

The experience of disability often serves to disrupt the expected or normal sequence of the life course. This is a life course characterised by stages and social roles such as being a child, student, employee, spouse, parent or colleague. Such roles may be viewed as markers of each life stage and are inherently subject to change and evolvement, and persons with disabilities often miss out on these experiences (Gerber and Kirchner, 2003). This distortion of the expected life course, where it results in limited opportunities and relative disadvantage, has repercussions into older age. On the other hand, persons ageing into disability will likely have experienced many of these life stages and occupied a variety of social roles. This in turn impacts on individuals' experience of disability in older age. However, expected social roles may also affect people ageing into disability negatively, especially where dependency and care challenge autonomy and independence (Coudin and Alexopoulos, 2010).

Social relationships are an area where life-course factors can be seen to result in differing experiences of community living for persons ageing with disability compared with persons ageing into disability. Social relationships, in particular spousal or longstanding partner relationships, are important for social connectedness and support (Warner and Kelley-Moore, 2012) and are a significant factor in the experience of community living in older age. The experience of disability earlier in life, or from birth, is oftentimes likely to have precluded marriage and children (Molton and Yorkston, 2016). According to Warner and Kelley-Moore (2012), marriage may be said to organise the social roles and interactions that take place across the life course. Therefore, persons with lifelong or earlier onset disability being less likely to have married or formed long-lasting personal relationships has implications in terms of transitioning into other traditional life-course roles and experiences, such as parenthood and independent living (Tumin, 2016).

The decreased likelihood of marriage for people with disabilities is associated with a number of factors included limited opportunities to meet potential partners, discrimination and negative attitudes (Tumin, 2016) as well as resistance from families. Indeed families can, perhaps unconsciously, steer persons with disabilities away from marriage and parenthood and other avenues of independence (Kelley-Moore, 2010), thus contributing to the narrowing of their opportunities for social relationships. Furthermore, that persons with disabilities may have experienced institutionalisation also contributes to the reduction in opportunity for social relationships. Indeed, the traditional avenues of interaction with potential partners, such as through work, hobbies or socialising, are often closed to persons with disabilities. While this may be slowly changing with increased social interaction and opportunities for persons with disabilities, for people who are now experiencing older age, the former was more likely to have been their reality.

Not having opportunity to marry or form other long-term relationships has consequences beyond the denial of the emotional support and enjoyment of a life partner. It impacts on financial security, family support and living arrangements, all of which are relevant for community living. Undoubtedly, institutionalisation or a lack of opportunity to live independently outside of the family home and having likely not married or had children, will have consequences in older age for persons ageing with disability (Bigby, 2002). Furthermore, even amongst persons ageing with disability who have married, fears can persist regarding a perceived lack of availability of future support leading to a heightened risk of institutionalised care should they lose the support currently provided by their spouse (Ellison *et al.*, 2011).

Persons ageing with disability may have relied on informal care from family members, who are themselves ageing and possibly ageing into disability, or siblings (Heller, 2019). However, as these networks of informal care are also ageing (Coyle *et al.*, 2016), it is a fact that aged parents may not be in a position to provide the same level of support as they did in earlier years. This has serious implications for the long-term living and support options for their adult children as they approach older age. It is a particular concern for persons with intellectual disabilities and their families, as they are often likely to have remained residing in the family home, which has ramifications for future independence and living arrangements.

Midlife housing disruptions can occur which remove the person with disabilities from the familiarity of home, neighbourhood and networks and therefore decrease the chances of being able to age in place (Bigby, 2008). The higher risk of institutionalisation for this group, and at a comparatively younger older age, has been highlighted and often results from the death or poorer health of the informal carer or inadequate supports in the living environment (Ouellette-Kuntz *et al.*, 2017). Inclusion Ireland, a national advocacy group for persons with intellectual disabilities, has highlighted scenarios brought to their attention through their advocacy work that demonstrate the need to ensure that supports are in place for both older persons with disabilities and their ageing carers (Inclusion Ireland, 2017a). These issues also arise in cases where siblings of persons ageing with disability or other informal supporters are themselves ageing and unable to continue in this supportive role. Also of consideration, therefore, is the likelihood that in addition to possibly requiring support from siblings, older persons with intellectual disabilities may themselves be providing care to older parents in the family home in a 'reverse care role' (Family Carers Ireland, 2015).

It is evident that more opportunities for persons with intellectual disabilities to live independently are required to reduce the increasing reliance on extended family care (Felce, 2016). Even where a person ageing with disability has experienced independent living in the community, this is likely, to some degree, to be facilitated through the informal support of family and friends. As the person ages, this support network is subject to natural shrinkage with the possible consequence of a reduction or even loss of informal support. In the absence of adequate informal support, state interventions may increase the likelihood of institutionalisation, especially in the absence of viable alternatives in the community, again linked to issues related to the availability of need-appropriate housing options.

2.4.5 Added Value

Exploring the phenomenon of disability in older age and the social issue of community living through the lens of the life-course benefits greater understanding. Life-course factors and trajectories are pertinent to this issue as the experience of disability in older age is not isolated from life's prior experiences. Furthermore, utilising the life course as an interpretive tool helps to explain the relative differences in experience of community living in older age that is significantly dictated by timing of disability onset. Kåhlin *et al.* (2015b), in the context of understanding the importance of the life-course perspective in respect of variables such as age and disability, reflect that ageing is a dynamic process where individual and social factors interact. Life-course factors and interaction with the institutionalised life course differs for people who are ageing with disability and people who are experiencing disability for the first time in older age. Understanding the relevance of these factors leads to a greater appreciation of the diversity of older persons with disabilities and the spectrum of life experiences and pathways that influence their experiences of disability in older age. Such appreciation is pertinent to the design and implementation of policy responses that recognise and respond to this diversity. McDaniel and Bernard (2011) highlight the potential of the life-course perspective as a policy lens, making visible options otherwise hidden, and demonstrating that policy interventions need not be major investments to deliver major gains.

2.5 Chapter Summary

This chapter has explored the particular characteristics of older persons with disabilities, being persons both ageing with and ageing into disability. Older persons with disabilities represent a relatively underexplored group in both ageing and disability research. Straddling sectors, how to support this group also represents something of a challenge in that neither the ageing nor disability sectors may adequately address their needs. This has implications for policy and highlights the need to capture the perspective of this group in research in order to respond to their unique situation. This rationalises the need for interdisciplinary research that captures the diversity of experience at the ageing/disability nexus. The research undertaken in this study concerns the topic of community living in the particular context of older persons with disabilities. Guided by this focus, the constituent elements of independent living, ageing in place and community inclusion have been explored. The particular relevance of these elements to the experience and maintenance of community living for older persons with disabilities has been highlighted, as have some of the difficulties in realising the goal of achieving these constituent elements. In the context of current resource constraints and a lack of joined-up thinking, achievement of this goal is not certain for all older persons with disabilities. This chapter has also explored the experience of community living in the context of the life course. This has entailed consideration of the life-course factors that shape and influence the experience of community living in older age. The life-course trajectories of older persons with disabilities can differ, in particular, as a result of timing of disability onset and the relevance of this has been highlighted. The next chapter explores community living policy in Ireland, the national context for the empirical study, against the backdrop of evolving policy trends in both ageing and disability and in the particular context of cultural, economic and international influences.

Chapter Three

Community Living Policy

3.1 Introduction

This chapter considers community living policy in Ireland for older persons with disabilities. This builds on the preceding chapter, which explored the components of community living. The empirical study, which forms a significant component of this research, and which will be presented in the chapters that follow, seeks to conceptualise the lived experience of community living for older persons with disabilities as well as to better understand the divergence of ageing and disability policy. The experiences captured in the study will seek to reflect the everyday experience of community living for the group of people who are both older and experiencing disability. The perspectives of policy and practice stakeholders, which will also be described in subsequent chapters, will illuminate the policy delineations that exist. Development of ageing and disability policies in Ireland, influenced by international trends, together with current shifts in focus are the backdrop against which community living is explored.

In this chapter, the focus is on considering the development of ageing and disability policy from their silo-specific standpoints. The influences of international developments and trends in ageing and disability will be highlighted both for context and domestic impact. Examples are used to illustrate the shifting direction of policies and their role in promoting or hindering the experience of community living for older persons with disabilities. Measures seeking to reform domestic policy in areas significant to community living, specifically deinstitutionalisation, home care and personalisation, are also considered.

Older people, with and without disabilities, overwhelmingly express a desire to live in their own homes and in their own communities (Ellison *et al.*, 2011). Indeed, the majority of older people in Ireland are living in their own homes

(Dukelow and Considine, 2017), albeit at times with the benefit of formal or informal support (Murphy *et al.*, 2015). The Irish Census 2016 suggested that 94.7% (577,171) of persons aged 65 and over were living in private dwellings in the community (Central Statistics Office, 2019). However, in Ireland, as in many other countries, the mechanisms by which community living is facilitated have been designed and delivered differently in the ageing and disability sectors (Leahy, 2018). This difference is rooted in historic, social and cultural understandings of ageing and disability, which predicated policy responses that were deemed appropriate in light of these prevailing views (McCormack, 2004). This difference also serves to reinforce the notion that one may either be older or disabled but not both (Bigby, 2008). However, as outlined in Chapter Two, disability and ageing are not homogenous states and such demarcations are not sufficiently reflective of the group of people who are both older and disabled, nor consequentially, sufficient to meet their particular needs (Leahy, 2018).

Conceptualising the society we envisage for older people, including older people with disabilities, necessitates interrogating some of our assumptions about what it means to age, what it means to experience disability, and what the appropriate policy responses should be (Zrinščak and Lawrence, 2014). Ultimately, this entails examination of the attitudinal, societal, political, legal and economic factors that shape and influence social policy. Against a backdrop of demographic change (Komp and Johansson, 2015a, Naue and Kroll, 2010), socio-economic factors and a growing appreciation of ageing and disability rights (Love and Lynch, 2018, O'Donovan *et al.*, 2018), Irish social policy is rethinking the appropriate response to the needs of older people and people with disabilities (Aspell *et al.*, 2019). This reorientation is evidenced in current exploratory consultations in areas of social policy that impact on the way in which older people and persons with disabilities are supported to live their lives in the community (Hanly and Sheerin, 2017, Fleming *et al.*, 2016).

This change is also reflective of international trends of reconfigured responses in both sectors (Aspell *et al.*, 2019, Power *et al.*, 2013). However, the extent to which these movements are happening within ageing and disability silos is still quite apparent, evidenced in Ireland by current consultations relating to personalisation and home care and in a broader sense by the seeming incompatibility of international policy frameworks to serve the needs of people who are experiencing both ageing and disability (Martinson and Berridge, 2015). Reconciling the reality of ageing for persons with disabilities within the ageing and disability sectors is undoubtedly a challenge, highly impacted by life-course factors and experiences, as explored in the previous chapter. Life-course factors linked to timing of disability onset influence the later life experience of older persons with disabilities, not least in terms of relationships and supports (Naidoo *et al.*, 2012, Kelley-Moore, 2010).

3.2 Silos and Synergies

3.2.1 Silo-Specific Standpoints

Ageing and disability are set apart and differences manifest in research agendas and policy priorities (Iezzoni, 2014, Cooper and Bigby, 2014). There is also a reluctance to merge traditionally separate sectors, each with their unique ethos, approaches, professional norms and models of service design and delivery in what may be described as an “arbitrary turf boundary” (Kennedy, 2000, p.123). Policy responses aimed at supporting community living evidence this siloed approach. Both sectors call for increased provision and access to services and supports in the community to facilitate their members to live, and age, in homes in the community. However, the framing of this issue, as well as the approach to achieve the goal of community living, is different in both sectors and indeed in the public perception of the issue.

Undoubtedly perception of need plays a pivotal role in how services are implemented and this can have a bearing in how older people and persons with disabilities are directed to services deemed appropriate to this need (Putnam, 2011). While the overarching aim of supporting independence may be common in ageing and disability, for younger persons with disabilities, this is most often promoted through initiatives of community integration and employment. For older people, it is couched more in strategies for positive ageing and ageing in place (Putnam, 2011, Verbrugge and Yang, 2002). Distinctions are also drawn when considering how programmes of support for younger persons with disabilities are often framed in terms of training whereas for older people discourse focuses more on assistance and 'doing for' the person (Putnam, 2011). Essentially, this is a question of enablement versus maintenance.

It may be owing to a perception that younger persons with disabilities have more pressing concerns than older people when it comes to traditional societal institutions such as family and employment (Putnam, 2011). A certain reluctance to locate disability within the successful ageing paradigm is mirrored in the hesitation to associate ageing with the disability rights movement for fear that ageing will become synonymous with disability. Successful ageing, built upon a premise of health, functioning and the maintenance of social roles (Kelley-Moore *et al.*, 2006) can leave little room for those who do not fit the mould. At the same time, the goal of equal societal participation inherent in disability policies is somewhat absent as a priority in policies for older people. In the latter, the priority in terms of participation is located more within the domains of the home (household tasks) or care (social activities in day centres) (Jönson and Harnett, 2015).

The disability sector calls for independent living facilitated through community-based services and supports including personal assistance (Fleming *et al.*, 2016) and is anti-institutional in approach (Kelly and Chapman, 2015). This encapsulates elements of equality, autonomy and independence, deemed pivotal to the realisation of the right to live independently and be included in the community as set forth in Article 19 of the CRPD. The ageing sector also supports independent living, although more commonly termed ageing in place (Grimmer *et al.*, 2015), again facilitated though community-based services and supports. However, instead of personal assistance, home-help services are prioritised in policy as a central component of supporting older people to remain living in their own homes (Timonen and O'Dwyer, 2009). By their nature, home-help services take place in the home and do not serve to support the older person to integrate into the community. Their orientation is that of domestic tasks and personal care rather than social support (Kiersey and Coleman, 2017).

The negative effect of silo-specific policy responses is clearly apparent in the case of older persons with disabilities. As highlighted in the previous chapter, this represents a diverse group with experiences largely influenced by life-course factors (Putnam, 2017). Persons with disabilities may face precarity in older age stemming from life-course factors resulting in insufficient resources (Kiersey and Coleman, 2017, Fitzgerald, 2007). Furthermore, a lack of opportunity to live independently outside of the family home, likely having not married or had children, will also have consequences in older age (Tumin, 2016). Reliance on state support in matters such as income, housing and healthcare can see persons ageing with disabilities at a disadvantage relative to their peers who are ageing into disabilities.

Equally, people who are ageing into disability can find their experience of disability dismissed as an unavoidable or almost expected consequence of long life. This may result in them being ineligible for certain benefits or supports (Nalder *et al.*, 2017, Rickli, 2016, Breitenbach, 2001). Putnam (2014) views this as an argument for closer alignment in areas of policy that have commonality of interest and relevance in both ageing and disability such as community living**.** Framing community living as a policy priority for older persons with disabilities necessitates exploring how ageing and disability policy have been shaped by ideology and evolved in recent times. Despite differences in development, there are mirrored images reflected in both sectors. The shift from dependency and passivity to rights and activism has affected both ageing and disability, albeit manifested differently.

3.2.2 Common Ground

Ageing and disability are interlinked processes, as “the chances of disability onset, disability remission and institutional residence vary as people age”

(Verbrugge and Yang, 2002, p.254). This succinctly epitomises the interlinked nature of ageing and disability and the commonalities of purpose and experience that can be seen in policy areas such as community living. Persons with disabilities and older people overwhelmingly share a desire to live in their own homes and participate in the life of the community (Craftman *et al.*, 2018). However, both groups can also experience fluctuating support networks, uneven resource allocation and unwanted or unnecessary admission to institutional settings (Allen *et al.*, 2014)

In common with all members of society, older people and persons with disabilities want to live independent lives and have the freedom to make choices (Löfqvist *et al.*, 2013). They also want to exert control over the decisions they make (Glendinning *et al.*, 2008). A significant minority of older persons and persons with disabilities rely on formal and informal supports in order to help them exercise their independence and autonomy**.** Supporting and enabling older people to be independent and included in their communities is a central element of social care policy (Barlow *et al.*, 2005). These supports are delivered in different ways in different countries depending on the prevailing features of the particular state. In social democratic welfare states, such as Sweden, personal assistance is well established (Clevnert and Johansson, 2007). In liberal welfare states, including Ireland, there has historically been greater reliance on informal family support and market-based supports (Gannon and Davin, 2010).

Both older people and persons with disabilities may require cross-departmental services in the community that will assist with the activities of daily life as well as their participation in the community (Molton and Yorkston, 2016). These commonalities are all the more pronounced for older persons with disabilities who are said to “straddle the systems” of ageing and disability (Coyle and Mutchler, 2017, p.685). In essence, although life-course trajectories may differ within the population of older persons with disabilities, owing in part to elements of ableism and ageism and consequential differing economic and social conditions, there are nonetheless commonalities of experience and opportunity within this group that represent common ground to be explored (Bickenbach *et al.*, 2012). Furthermore, although the ageing and disability sectors have their individual strengths in information and service provision, there is still a need for both sectors to understand the common particular needs of their members who belong to both sectors (Coyle and Mutchler, 2017). This is important given that the ageing sector may not have the requisite understanding to deal with the particular challenges faced by persons ageing with disability and neither might the disability sector have the tools to help them navigate older age (LaPlante, 2014). Exploring common issues such as community living is therefore a rationale exercise.

3.2.3 International Innovations

Growing awareness of the need to capture the diversity within groups, such as people who are ageing and have disabilities, in order to deliver more rounded policy responses can be seen in innovations relating to community living policy. A development in this regard has occurred in the United States. The US Administration for Community Living (ACL) was established in 2012 by bringing together the Administration on Aging, the Office on Disability and the Administration on Developmental Disabilities (https://acl.gov/). ACL was founded on the principle that older people and persons with disabilities should be able to live where and with whom they choose and have the opportunity to fully participate as included and valued members of their communities. Its objective is to facilitate the independence and well-being of older persons and persons with disabilities in the community across the lifespan (Boutaugh and Lawrence, 2015). Since its inception, ACL has grown significantly and a number of programs aimed at older people and persons with disabilities have been transferred under its remit. Furthermore, the 2014 Workforce Innovation and Opportunities Act moved the National Institute on Disability, Independent Living, and Rehabilitation Research and the independent living and assistive technology programs from the Department of Education to ACL. ACL has introduced a variety of programmes aimed facilitating community living and supporting family carers (Link, 2015). Merging ageing and disability in this way recognised the commonalities of cause and experience in the realm of community living and provide an example of bridging in practice. It has been recognised as a means of focusing attention and resources on older people and persons with disabilities across the life course (Heller, 2019, Heller *et al.*, 2015).

Furthermore, merging these areas acknowledged the diversity of communities and the need to ensure that older people and persons with disabilities are afforded the requisite supports and services to continue to lead independent and supported lives in their communities. This was recognised as an issue of increasing prominence given the increasing numbers of older people and persons with disabilities in society and the need for community-based services and supports that are responsive to their needs. Community living is only possible if the community is open to the diverse needs of all its members, as without this institutionalisation and residential care can become the default option for people who cannot maintain their lives in the community without some degree of support. ACL was founded on this rationale and serves as an example of where a 'no wrong door' policy can operate as a ladder out of silos, merging the interests and needs of different groups in society in pursuit of a common cause that benefits society as a whole (Siegler *et al.*, 2015).

3.3 Policy Trends

In order to understand why older persons with disabilities may find neither ageing policy, nor disability policy, alone adequately addresses their particular needs, it is necessary to understand how policy emanating from both sectors has evolved. As outlined in the previous chapter, ageing and disability have long been marked apart in research, policy and practice and there have been calls for greater cooperation between the sectors (Iezzoni, 2014, Putnam, 2014, Bickenbach *et al.*, 2012, Berridge, 2012, Carling-Jenkins *et al.*, 2012). Indeed, commonalities of purpose and experience would indicate both need and potential for greater interdisciplinary research, strategic action and policy development (Kennedy, 2000). Arguably, the lack of such cooperation is rooted in traditional perceptions of ageing and disability and reluctance on both sides to see a conflation of ageing and disability. Westwood and Carey (2018) also point to the marked absence of the voice of older people in disability and the voice of persons with disabilities in ageing as leading to the lack of collaboration and interdisciplinary research.

Older people are not well represented in disability organisations, despite making a significant proportion of persons with disabilities (Priestley and Rabie, 2002), nor are they leading actors in disability activism (Wiles *et al.*, 2011). This may be rationalised by considering the policy agenda that has been pursued by the disability sector. The disability sector has championed equal access and participation in all areas of life, not least education, employment and independent living, and pursued anti-discrimination legislation (Barnes, 2012). Equality, autonomy and independence have been the cornerstones of this policy agenda (De Wispelaere and Walsh, 2007). The focus on these domains has had the effect of framing disability to the possible exclusion of older people (Glasby, 2017), particularly people who have come to experience disability for the first time in older age.

For older persons who have aged into disability, the struggle to attain equality of access and participation in these domains will likely not have featured in their life experience in the same way as for people for whom disability has long been a feature of life. Therefore, focussing on these issues in disability activism has served to exclude older persons with disabilities, particularly people ageing into disability, who may have led a life that corresponded with the traditional life-stage markers. In this way, activists or policy makers do not always consider ageing a significant factor in disability. In Sweden, for example, evidence points to the relative exclusion of older people from disability activism (Kåhlin *et al.*, 2015b). Furthermore, it has been argued that older people in Europe are not as strong at mobilising as a social movement or interest group as their counterparts in the United States (Carney, 2010).

Equally, the ageing sector has typically striven to avoid the conflation of age and impairment that so often relegates the ageing population to the status of a frail burden that monopolises societies' scarce resources (Hurley *et al.*, 2017). Ageing has prioritised the avoidance of impairment and disability through policies that promote successful or active and healthy forms of ageing (Holstein and Minkler, 2003). Framing ageing in such a manner has the unavoidable consequence of excluding older persons with disabilities who do not conform to these measures of successful ageing. This criticism was reflected in the findings of Gibney *et al.* (2019) in the Department of Health commissioned study on indicators of positive ageing in Ireland. Their findings supported the contention that a single standard of ageing does not necessarily reflect diversity of experience and may be harmful to already marginalised groups, such as older persons with disabilities. In order to consider how greater cross-sectorial cooperation can be achieved, it is necessary to understand the background of both sectors and some of the factors that have shaped ageing and disability policy in recent times.

3.3.1 Ageing Trends

Ageing policy responses have been influenced by a shifting focus over the past number of decades. As community care became increasingly regarded as a better alternative to institutional care, there was a growing move towards policy responses that promoted community for both older people and persons with disabilities. Supporting older people to live in the community rather than in residential institutions was seen as a more cost-effective approach (Means *et al.*, 2008). However, the legacy of the former institutional approach that preceded notions of care or support in the community arguably persists in power imbalances, lack of choice and underlying service ethos (Glasby, 2017). However, more recent policy shifts may be viewed as more empowering, albeit with caveats regarding inclusivity for those who do not typify the stereotype envisaged by current policies.

The relative side-lining of older people as mere social welfare concerns (Kendig *et al.*, 2013) began to change in the later years of the twentieth century. Developments such as the United Nations Principles for Older Persons (United Nations, 1991) and the 2002 Madrid International Plan of Action on Ageing (MIPAA) (United Nations, 2002) were significant. Adopting a more rights based approach to the position of older people, these developments served to advance the profile and interests of older people on the international stage (Kendig *et al.*, 2013).

From an international policy perspective, the perception of ageing as a time of decline and dependency has been replaced with an image of ageing as a time of continuing social contribution and individual achievement (Raymond and Grenier, 2013). Inherent in this is the implied expectation that older people themselves will make an effort to be socially engaged and active in older age. Participation is therefore a key component of this policy trend and reflects a general move towards individual responsibility and self-sufficiency. Successful and active ageing are the dominant paradigms founded on this principle of activity (Foster and Walker, 2014). Foster and Walker (2014) distinguish successful and active ageing by their prominence in the United States and Europe respectively. Both successful and active ageing are powerful concepts in research, policy and practice (Timonen, 2016) and may be construed as positive discourses that now dominate in these areas (de São José *et al.*, 2017).

The popularity of the concept of 'successful ageing' may be credited to Rowe and Kahn, whose 1987 article on human ageing distinguished usual and successful ageing and proposed recommendations with a common theme of health promotion as a gerontological goal (Rowe and Kahn, 1987). Further elaborations have followed over subsequent years, more recently an editorial update for the 21st century (Rowe and Kahn, 2015). The latter acknowledges criticisms of the model, including the lack of explicit reference to other social factors, including both personal and environmental characteristics, which impact on a person's ability to age in a manner deemed successful. However, they view these criticisms as "recommendations for future work" (Rowe and Kahn, 2015, p. 595) and suggest three goals for scholars addressing successful ageing at individual and societal levels in this time of population ageing: re-engineering core social institutions; adopting a life-course perspective; and focussing on human capital. Carpentieri *et al.* (2016) concur with such a conceptual expansion given the general appeal of the concept.

Active ageing, on the other hand, has been the model most widely adopted in Europe as a policy response to population ageing (de Sao Jose *et al.*, 2017). It may be viewed as the dominant construction of ageing well in the European Union (Van Dyk *et al.*, 2013). Active ageing is premised on facilitating older people to remain healthy, continue in employment and participate in community life for longer. Within the active ageing agenda were developments such as the UN designation of the Year of Older People 1999 and the European Commission's policy focus on the challenges of ageing in the 1999 policy document 'Towards a Europe for All Ages', which, while leading to policy priorities that were wider than just employment, nevertheless focused primarily on employment and extending working life (Foster and Walker, 2014). Van Dyk (2014) commented that active ageing was conceived not merely as an economic necessity but also presented as being of societal and individual benefit.

The World Health Organization employed the term 'active ageing' and its 2002 'Active Ageing Policy Framework' linked activity and health, focusing on employment and productivity as well as health and participation in all facets of society including social, economic, cultural, political and civic life (Foster and Boxall, 2015). This interpretation of active ageing is significant as its scope extends beyond the realm of labour market participation. By focusing on participation and the continued engagement of older people in society, the active ageing paradigm challenges the notions of decline and loss (Foster and Boxall, 2015). Foster and Walker (2014) contend that it connotes a more holistic model than successful ageing, while also acknowledging that its focus has been largely economic in practice, thus narrowing its applicability somewhat to those in employment. Clarke and Warren (2007) called for a focus on individuals' needs and inclusion of a life-course perspective reflective of individual experience and desires. This would afford a more encompassing interpretation of 'active ageing' that need not be overly zealous or ambitious in terms of engagement. Expanding upon this, Gunnarsson (2009) in a Swedish study on the everyday lives of older people found that 'being active' is a multifaceted concept that changes over time and differs amongst individuals. Van Dyk *et al.* (2013) challenge the dominance of active ageing as a policy paradigm with findings that suggesting that older people find multiple meanings in ageing well, with few tied to productivity and activity.

The extent to which either successful or active and healthy ageing models are inclusive of the disability experience is debatable. Van Dyk (2014) reflects on how they share the idea that there is both a potential to influence the ageing process and an individual responsibility to do so. However, older people who are dependent are as marginalised as ever within these models (van Dyk, 2016). Impairment and disability do not sit well with the common interpretation of ageing within these models and rather are viewed as something to be avoided or staved off for as long as possible (Martinson and Berridge, 2015). Ageing successfully does not include the visible apparatus of disability, such as wheelchairs and walkers (Martinson and Berridge, 2015, Larsson, 2013). This apparent incompatibility is notable given that many people with lifelong or early onset disabilities are increasingly living into older age, establishing a need to consider how people with these characteristics can be supported to age successfully (LaPlante, 2014).

Research (Hildon *et al.*, 2008) has shown that successful ageing need not be equated with good health and that older people can be supported within their social contexts to adapt to changing circumstances, retain their sense of identify and maintain a good quality of life. Westwood and Carey (2018) explore this issue from a social justice perspective and concur with the view that current constructions are both ableist and ageist. They contend that in order to fully explore how to live well, there is a need to acknowledge the realities of ageing with and ageing into disability and to move beyond the "false narrative of a disability/disease-free older age" (Westwood and Carey, 2018, p. 239). Older people with disabilities may be led to view themselves or feel perceived by society as being situated outside of these models. They can therefore struggle to find their place in policy responses framed within these models. Indeed there is an inherent and individual fear of ageing with a disability promoted through such models that represents a form of ageism in itself (Holstein and Minkler, 2003).

Ageing models predicated on the notion of activity and productivity can be an uncomfortable fit for older persons with disabilities, exerting unrealistic expectations and pressures and ultimately furthering their sense of exclusion. Foster and Walker (2014) highlight that the diversity of the older population may not be captured by these models and indeed it is the heterogeneity of the older population itself that makes such concepts difficult to measure. Indeed this is important given that the heterogeneity of the older population is seen not only demographically but socially and economically (Bernard and Scharf, 2007).

In considering active ageing in the context of older persons with intellectual disabilities, Foster and Boxall (2015) have highlighted that this perspective has been largely absent from discourse and the exclusion of older persons with intellectual disability from mainstream ageing policy needs to be addressed. They contend that the focus on employment and the economic dimension of the active ageing model excludes people whose life course has not afforded opportunity for economic participation. They call for account to be taken of the diversity of life experiences of all older people so that active ageing may be a more encompassing and effective policy tool, and significantly one, which allows activity to be more broadly construed.

Boudiny (2013) also advocates the inclusion of diversity in the active ageing paradigm so that active ageing at different stages of life can be accommodated. For people who may be deemed to be more dependent, this may necessitate polices focusing on a wider notion of engagement with life rather than a narrow focus on economic engagement or physical activities. Holstein and Minkler (2003) also reflected on the need to be more reflective of life-course experiences and opportunities and how they impact on the ageing experience. Gibney *et al.* (2019) highlight that the interpretation of positive ageing applied in Ireland's

NPAS extends beyond successful or active ageing and incorporates consideration of the societal, political and economic conditions that impact on the ageing experience. Park (2011) also highlights this need for policy responses to recognise contextualised lived experiences of older people.

3.3.2 Disability Trends

The traditional response to the needs of persons with disabilities was formulated on notions of charity and welfare dependency that served to exclude persons with disabilities and deny their equal rights and participation in mainstream society (Quinn and Degener, 2003, Van Aswegen, 2019, Mabbett, 2005). This was also the traditional response in Ireland (Fleming *et al.*, 2017). In challenging this, the recognition of their rights rather than care was the goal for persons with disabilities (Shakespeare, 2000). Changes in societal responses to disability and the perception and treatment of persons with disabilities are reflective of activism that resulted in evolving 'models' of disability.

Activism called for a shift in the treatment of persons with disabilities as well as the approach to disability policy. A particularly strong example of this in the context of community living was the success of the independent living movement in the US, which challenged inaccessible educational opportunities and resulted in the formation of the first Center for Independent Living (CIL) at Berkeley in 1972, a model since adopted elsewhere, including in the UK and Ireland (https://www.thecil.org/history). In the realm of legislation, the Americans with Disabilities Act, 1990 (ADA) was also a significant development. The ADA recognised the particular discrimination faced by persons with disabilities and was formulated on the concept of 'reasonable accommodation', bringing focus on overcoming barriers to the right to independent living in the community. Although not without criticism, Kanter (2015) acknowledges that the ADA succeeded in bringing about increased awareness of disability issues and greater access to physical infrastructure and services, as well as offering guidance for the drafting of the CRPD.

The influence of the disability rights movement in the US was felt across the

Atlantic and motivated demonstrations in the UK, highlighting the inequalities faced by persons with disabilities in society (Shakespeare, 2006). Fletcher and O'Brien (2008) discuss the influence of the activism in the US that was a precursor to the ADA on similar calls for rights in the UK. The Disability Rights Commission (DRC) in the UK in 2002 also adopted the aim of a right to independent living for persons with disabilities (Power, 2013). Barnes (2014) categorises the independent living movement as a challenge to established thinking on disability with the potential to enhance the quality of life of not only persons with disabilities but also other structurally disadvantaged groups in society, such as older people. This change in established thinking is reflected in the models of disability that prevailed at different stages over the last number of years (Chadwick *et al.*, 2013), Garcia Iriarte (2016) reflects that disability, as an evolving concept, may be explained through the various models that prevail and impact on policy reform. Within the context of charting disability reform, of particular significance are the medical, social and human rights models of disability.

Medical Model

The traditional response to the needs of persons with disabilities was overly paternalistic and dominated by the medical model, which viewed disability in individual terms of medical impairment (Barnes, 2012). This was reflected in policy responses in many countries that prioritised institutionalisation and rehabilitation rather than independence and inclusion. This resulted in a lack of choice and control and respect for personal autonomy. Within this model, disability is perceived as an individualised problem and locates focus there rather than with interventions to change the disabling environment (Garcia Iriarte, 2016). Essentially within the medical model, medical rather than societal solutions are sought (Wolbring, 2001).

Persons with disabilities were viewed primarily for their lack of ability and as passive recipients of care. For many persons with disabilities in Ireland, this resulted in segregation from the institutions of life such as education and employment. In addition to special schools (Carpenter and Shevlin, 2004), persons with disabilities were often placed in special residential institutions. Segregated employment in the form of sheltered workshops also ensured that persons with disabilities were not afforded the same rights and benefits as ordinary workers in the state (Noonan Walsh and Lynch, 2004). Effectively, there was a specialised response for special needs (McCormack, 2004).

Social Model

The social model of disability was conceived in response to what was viewed as the individual medicalised response to disability. Mike Oliver coined the phrase in 1981 as a means of redirecting attention to the way the physical and social environment served to limit persons with disabilities (Barnes 2012). As the social model, which highlighted the role of barriers in society in the disablement process, gained traction, the disability movement also grew, with activism calling for a different response in society formulated on accessibility, inclusion and non-discrimination (Oliver, 2013). The social model views disability as a social construct with the problem arising from discriminatory policies as opposed to the individual (Degener, 2016).

Mabbett (2005) reflects on the role of the social model as a transnational focus for the international disability rights movement. Barnes (2012) calls the social model a “heuristic device” or an aid for understanding. It is a tool to gain insight into the disabling effects of society with a view to eradicating them though effective policies and practices (Barnes, 2003). The social model has been credited with the potential to enhance the situation of older persons both ageing with and into disability (Jönson and Harnett, 2015). Lawson and Priestley (2016) position the social model of disability within the societal structures and systems that serve to exclude persons with disabilities and argue that is an avenue through which such oppressive barriers may be challenged. However, it is not without criticism, perhaps most notably the argument that it neglects the individual experience of impairment (McGrath *et al.*, 2017).

Utilising the social model as a tool for reform, focus was orientated towards how persons with disabilities could be supported to participate in society as rights bearers on an equal basis with others. Oliver and Barnes (2010) credited the social model as being a key influencer on social policy generally, and disability policy more particularly. The social model and associated disability rights activism therefore had a significant impact on reframing of policy responses to the needs of persons with disabilities (Barnes, 2012). The social model was utilised in the struggle for equal rights for persons with disabilities and the pursuance of anti-discrimination laws. It now forms the basis of European Union disability policy (Degener, 2016). The disability rights movement and activism was influenced to a large extent by the rejection of institutional care and instead spurned calls for independent living (Barnes, 2012).

Human Rights Model

The CRPD became operational in 2008 and was the first human rights treaty of the twenty-first century. Bickenbach *et al.* (2017) highlight that the CRPD demonstrated that all institutions of the modern social state must be engaged in order to address disability as a matter of societal obligation. Undoubtedly, the CRPD represented a paradigm shift in the perception and treatment of persons with disabilities, recognising them as equal rights holders and providing guidance on how these rights could be supported by member states (Kanter, 2009). Degener (2016) views the human rights model as going beyond the social model, with the CRPD being a manifestation of the former. On the basis of six arguments, Degener differentiates the human rights model from the social model. Her arguments include acknowledgement of both the value of impairment as part of the human condition and the role of other identity factors, such as age, in the disability context. However, she is keen to emphasise the enormous contribution that the social model made in drafting the CRPD. She contends that the aim of the human rights model of disability is to further the social model but concedes that this shift is in its early stages (Degener, 2016).

The ratification of the CRPD in Ireland in 2018 was the culmination of years of hard work and campaigning on the part of disability activists, persons with disabilities, their families and representative organisations. The CRPD calls for the full inclusion and participation of persons with disabilities in society on an equal basis with others. The value of the CRPD lies in the onus it places on states to justify their policies in advancing the rights of persons with disabilities and for the guidance it provides on what a rights-based approach in policy means (Quinn, 2009). Ireland is now bound in international law to uphold the rights contained in the CRPD, making it an important instrument in the toolkit for persons with disabilities, including older persons with disabilities, in having their rights recognised and respected. However, although these principles are increasingly reflected in political rhetoric and policy documentation, there is still much to be done to achieve real and sustainable change in the lives of persons with disabilities in Ireland, not least in relation to achieving meaningful community living. Indeed the policy implications of ratification remain unclear (McCausland *et al.*, 2017).

3.4 Irish Social Policy

3.4.1 Introduction

The extent to which policy responses are reflective of the fluctuating nature of need has a correlation to the extent that older persons with disabilities can experience independence and inclusion in the community (Kåhlin *et al.*, 2015b). With an increasing older population comes an impetus to put in place supports that address their needs (Wren *et al.*, 2017). However, even countries with seemingly robust ageing policies, such as Sweden, are finding that their formal care has not managed to keep up with the increasing older population, as evidenced by reduced coverage rates of both institutional and home care (Schön *et al.*, 2016). Indeed cost containment in long-term care has become a pressing concern for policy makers across European countries (Da Roit, 2012). Moreover, there has been both a re-familisation of care and a marketisation of care, the latter largely predicated by neo-liberal ideas concerning consumer choice and competition (Dahlberg *et al.*, 2018). This has also been reflected in Ireland with increased private, for-profit service providers entering the market, thereby altering the social care landscape (Mulkeen, 2016, Cullen, 2019). This too impacts on the community living experience of older persons with disabilities.

It is necessary to view the development of social policy relating to ageing and disability in the context of the peculiarities of the Irish welfare state as well as the social, cultural and economic changes that have taken place in Ireland over the past number of years. These factors impact on the fabric of Irish society, which is the backdrop for social movements and social change. The shifts that have taken place in Ireland have been many and profound. A growing awareness of the rights of marginalised and vulnerable groups in Irish society has largely driven these shifts and has brought issues of equality to the fore of the public consciousness and onto the political agenda. Confrontation with failings of the past and questioning long-held beliefs have hastened challenges to the status quo. As a nation and as a people, modern Ireland has looked inwards and re-examined the type of society it seeks to be.

Although there has been much progress over a relatively short space of time, as evidenced by recent referenda on topical issues with a strong equality dimension, the positions of many groups in society remain precarious and susceptible to the vagaries of political will, public mood and fiscal health. These internal forces, as well as external factors, including international obligations and commitments, dictate policy responses. The following sections will consider the nature of the welfare state in Ireland as well as the changing fabric of Irish society in order to contextualise some of the developments in ageing and disability policy. In charting the evolution of ageing policy in Ireland from the second half of the 20th century to the current period, it is possible to discern the shifts that have taken place and the influence of both internal and external factors.

3.4.2 The Welfare State

The welfare state may be described as "a set of institutionalised provisions designed to meet the social and economic needs of citizens in a democratic society" (Powell, 2017, p.13), with a strong association with the principle of social justice and which seeks to redress poverty and income inequalities. While Ireland has traditionally been referred to as a welfare state, its place in the established welfare regime models has been difficult to pinpoint. The Irish model does not fall neatly within the established liberal, corporatist or social democratic welfare state clusters as set out by Esping-Andersen (1990) in the influential "Three Worlds of Welfare Capitalism". Ireland would seem to represent a hybrid model that has been influenced by its near neighbour Britain as well as by the United States. Indeed, Powell (2017) highlights the role of Ireland's colonial past and status as an English-speaking country in its Anglo-Saxon liberal welfare state leanings.

Powell (2017) notes the impact of neoliberalism on the welfare state that has also been felt in Ireland. Neoliberalism prizes personal responsibility and self-reliance and challenges the concept of the 'social', seeking to put responsibility back on the community and the family rather than the state. However, Norris (2016), while acknowledging the impact of neo-liberalism on the modern welfare state, points to the continued legacy of the Irish 'property-based welfare system' and the manner through which the objectives of such a regime were continued by the Government in more recent times through more marketised methods, such as subsidies to developers and unregulated lending. Norris (2016) connects the property-based welfare state to the prominent position that the family has occupied in Irish society, enshrined in the 1937 Constitution, (Bunreacht na hÉireann, 1937) with state and church support. Indeed, coupled with the role of the Catholic Church in Irish society, the primary role of the family has been a strong influencer in shaping social policy responses.

However, it must also be acknowledged that Irish social policy has been influenced by modernisation, secularisation, globalisation and Europeanisation in more recent decades (Kirby and Murphy, 2011, Hay and Smith, 2005, Layte *et al.*, 2005). Powell (2017) points to the important role of social policy as a framework for the welfare state and cites the fact that health inequalities and homelessness were key issues in the most recent Irish general election, 2016, as evidence that the welfare state still has popular support. Nonetheless, Powell (2017) also highlights that there is a crisis of legitimacy facing the modern welfare state, where financial gain challenges the notions of decency, fairness and justice in defining what makes a good society. Ultimately, this speaks to the type of society Ireland purports to be and this debate lies at the heart of democratic societies. The extent to which social policy has recovered from its subordination to economic policy during the boom period (Powell, 2017) is debatable with notions of usefulness and productivity creeping into social policy in various guises such as proposed grants for grandparents to look after grandchildren and extensions to the age threshold for state pensions. Walker and Maltby (2012) highlight the association that has traditionally existed between development of welfare states and older people, with pensions being one of the foremost institutions of the welfare state.

3.4.3 Changing Attitudes and Cultural Shifts

Ireland has changed significantly over the past number of decades. As a country it has become less insular and more internationally orientated, owing not least to membership of the European Union and increased activity in international matters such as trade, politics and human rights. At a societal level, Ireland has also undergone significant change. The role of the Catholic Church in health and education has diminished demonstrably with increasing calls for further separation of Church and State in such matters (O'Flaherty *et al.*, 2018). Revelations of historical abuse in institutional care, mistreatment of unmarried mothers and even the deaths of babies in Catholic Church run mother and baby homes have hastened this decline. The failings of the past have been put under stark spotlight and this has impacted on the nation emotionally and psychologically. Overall, Ireland has moved from church dominance to what Fitzgerald (2012, p. 1373) termed “a confident pluralism”.

Economically, Ireland has also experienced highs and lows. Having come through economic hardships in the 1980s, the arrival of the ‘Celtic Tiger’ saw an era of unprecedented prosperity in Ireland. This came crashing down in the late 2000s owing to a collapse of the property market and a failure to regulate banking (Fitzgerald, 2012). The recession that followed saw massive emigration of younger people, severe budgetary cuts in health and social care and other austerity measures imposed as part of Ireland’s recovery plan overseen by ‘the Troika’ consisting of the EC, ECB and IMF (Walsh *et al.*, 2015, Timonen *et al.*, 2012b)**.** However, (Dukelow, 2015), contends that the measures imposed merely served to reinforce the general direction of domestic policy objectives already undertaken or planned. Undoubtedly, persons with disabilities did not fare as well during the period of economic prosperity (Fitzgerald, 2007) and furthermore the austerity in its wake saw social policy undermined with reductions in public expenditure (Walsh *et al.*, 2015, Allen, 2012). Although social protection is the largest category of public expenditure, Ireland only spends 71.6% of peer-country average on a per capita basis, largely attributed to significant under-spends on older age benefits, sickness and disability and social exclusion (McDonnell, 2017).

Austerity impacted older people not only directly with regard to their social benefits, but also indirectly in familial support arrangements. Many older people were left with no choice but to step in to assist their adult children financially, in addition to support they may already be providing in areas such as childcare or care to their own aged parents. Research on intergenerational solidarity, using a constructivist grounded approach, considered the impact of austerity *(Carney et al.,* 2014). For the older adult (51-74) age group, there were significant informal transfers of resources to the younger generation as well as considerable support being provided in terms of both child and elder care. Overall, social policy has evolved in these decades of social and economic change and against this backdrop of highs and lows, prosperity and austerity, confidence and controversy.

3.4.4 Ageing Policy

As highlighted in the preceding section, Ireland has seen significant change over recent decades. Within a broad context, the experience of ageing is dictated by societal attitudes and perceptions as well as economic priorities and policies. In terms of attitude and perception, it is necessary to acknowledge shifts in how older people are perceived and how this impacts policy agendas. Welfare states are premised on an intergenerational contract whereby work in early years reaps state support in older age and for this contact to be honoured, there must be both agreement across time and an acknowledgment of its inherent fairness (Hurley *et al.*, 2017). However, an increasing older population and a need to respond to the so called 'challenge' of ageing has led to predictions of unsustainability and inequity that serve to challenge this intergenerational contract. This is reflected in the crisis rhetoric associated with the long term needs of older people seen in recent times (Kelly, 2016).

Komp and Van Tilburg (2010) reflect on how ageing populations are presumed to challenge the sustainability of the intergenerational contract, given increasingly visible demands. A consequence of this is the growth in ageing models formulated on activity, usefulness and productivity whereby older people who age well or successfully are not a burden whereas those who require support are. An older age largely framed in terms of activity, productivity and health marginalises older persons with disabilities, who do not easily conform to ideals of successful or healthy or active ageing. This section sketches the evolution of ageing policy in Ireland over recent decades, using illustrative examples in order to anchor the experience of community living for older persons with disabilities in the ageing context.

In Ireland, the commitment to supporting older people to live and age in their homes and communities has been present in spirit, if not always in execution, for many years. This commitment has been government policy for many years and is reflected in a number of policy documents, as early as 1968 and *The Care of the Aged Report* (Committee, 1968) to the current Programme for Partnership Government (Department of the Taoiseach, 2016). Undoubtedly, political rhetoric supports a move towards a greater provision of community-based services and supports and the promotion of the principles of autonomy, independence and choice for older people and persons with disabilities. This represents a shift to a more rights-based ideology of support from the traditional care perspective.

Given the prominence assigned to the family in Irish society, it is perhaps unsurprising that support for older people was traditionally largely left to family members. Social values anchored in family and responsibility, compounded by the dominant Catholic ethos, normalised such arrangements. Furthermore, larger families and lower rates of female participation in paid employment outside the home helped facilitate such care arrangements as there was a ready supply of informal carers, often daughters and daughters-in-law, available to provide care in the home as older relatives became more dependent. Change was slow, but was evidenced in a number of policy documents over the years that marked the emergence of a more concerted effort to establish social policy in ageing.

In 1968, the Care of the Aged Report was significant and innovative for its basic premise that older people should be supported by policy to live and age in their own homes for as long as possible. This marked a significant departure from the "haphazard and institutionally biased nature of care that went before" (O'Shea, 1993, p.77). Such policy would necessitate investment in community-based supports as well as in services, such as home help and a more integrated approach to care, wherein family and formal care would be complementary rather than substitutable (O'Shea, 1993) and indeed such a combination has been highlighted as fundamental to community-based care (Hanly and Sheerin, 2017).

The Care of the Aged Report served as a blueprint for subsequent policy developments, viewing older age for more than dependence and decline and recognising diversity of need and the requirement to have formal services in the community to support older people (Walsh et al, 2015).

Twenty years later, *The Years Ahead: A Policy for the Elderly* (Department of Health, 1988) represented a significant development of social policy in ageing. Adopting a multidimensional perspective of ageing, it can be regarded as the first comprehensive policy framework for ageing in Ireland, touching on many areas including long-term care, health services, housing and services (Walsh *et al.*, 2015). Furthermore, the report called for a more collaborative approach between informal carers, the voluntary sector and state agencies, although the focus was still more on providing services for older people than a more consultative support ethos (Walsh *et al.*, 2015). As trends moved towards positive ageing and active ageing, as advocated by international agencies such as the World Health Organisation (WHO), Irish policy was not immune to these shifts. In this respect, the *National Health Promotion Strategy for Older People* (Brenner and Shelley, 1998) supported such an approach with a marked focus on social interaction, ageism and health as key areas to be attended to.

More recently, increasing focus has been applied to the issue of rights and to ensuring that older people are afforded due dignity and respect in matters including long-term care and support. A number of recent policy documents are evidence of the further pursuance of this ideological shift in relation to ageing policy in Ireland and are of relevance in the context of community living.

National Positive Ageing Strategy

The National Positive Ageing Strategy (NPAS) of 2013 (Department of Health, 2013), is a cross-departmental government policy, which sets out Ireland's vision for ageing, outlining goals and objectives that touch on a number of policy remits, including social services and social participation. In the context of community living, Goal 3 of the four national goals of the NPAS is 'to enable people to age with confidence, security and dignity in their own homes and communities for as long as possible'. The corresponding objectives to this goal include facilitating older people to live in homes that are safe, secure, affordable and well maintained and, furthermore, match individuals' physical and social needs. This is particularly relevant in the context of older persons who are experiencing disabilities, as the home may not always be designed in an accessible way and the older person may lack the personal and monetary resources to make the necessary adaptations to continue to live in their own home.

The objective of combatting elder abuse through awareness raising and support services is also important in the context of community living in situations where older people with disabilities are receiving support in the home (Phelan, 2014). There is an increased potential for abuse, including financial abuse, in such instances and carers, including family members, may perpetrate this abuse, sometimes unwittingly, but at other times in a more deliberate and systemic manner (Lowenstein *et al.*, 2009, Naughton *et al.*, 2010, Biggs *et al.*, 2009, Pickering *et al.*, 2018). Awareness and understanding of the human rights of older people is often lacking in these informal care relationships (Love and Lynch, 2018). Combatting all forms of abuse and denial of rights is a growing issue and important if older persons with disabilities are to continue to live and age in their own homes safely and confidently.

Another objective of relevance in the context of community living for older persons with disabilities is that community spaces be designed in an age-friendly manner so that older people may feel confident and welcome in the community and therefore feel a part of the community. This particular policy objective aligns to the growing age-friendly cities and communities' movement (World Health Organization, 2007) in which Ireland has played a role (Walsh *et al.*, 2015, McDonald *et al.*, 2018, Walsh, 2014). Currently, 31 city and county local authority-led age-friendly programmes are operational and there is a commitment to imbed the philosophy in measures including sustainable and lifetime housing

(Department of Housing, Planning and Local Government & Department of Health, 2019).

The NPAS is notable for the extensive consultation that accompanied its drafting, in some ways mirroring the disability rights call to include the voice of the persons for whom the policy is ultimately intended to benefit. This has been highlighted by some commentators as a reflection of the change in how older people are viewed by policy makers (Martínez-Leal *et al.*, 2011). However, the call for all people to take responsibility for their own ageing could also be construed as a move towards an individual approach in such policy matters indicative of the shift towards individualisation of risk and responsibility (Walsh *et al.*, 2015).

National Dementia Strategy

Dementia policy and planning is an example of where the ageing and disability sectors can collaborate to achieve better outcomes for the person. The National Dementia Strategy (NDS) (Department of Health, 2014) was launched in 2014 with the aim of increasing awareness, early diagnosis and interventions as well as community-based supports. It was highly influenced by the 'Creating Excellence in Dementia Care Report' (Cahill *et al.*, 2012), which provided an evidence base of national and international best practice in dementia care. It also benefited from the very considerable investment of over €33 million from The Atlantic Philanthropies, which facilitated partnerships with stakeholders that spurred the development of the NDS (O'Shea *et al.*, 2017).

The NDS recognised that people with dementia could, and indeed should, continue to live well in the community with the right supports, and, furthermore, although dementia required medical interventions, the societal element should not be neglected. To this end, it recognised the role of the community in supporting a person with dementia to remain living in their own community. The NDS further recognised that communities are central to ensuring that persons with dementia can continue to live in their own homes, as the combination of formal and informal supports in the community deliver the best outcomes for the person. The NDS acknowledged the importance of services such as home help; home care packages and community day centres in supporting family caregivers to continue to offer support to their family members in their own homes and communities. In relation to 'Integrated Services, Supports and Care for People with Dementia and their Carers', the NDS listed amongst its objectives that people with dementia be supported to continue to live in their own homes, with the necessary community supports, and maintain their roles and relationships in the community for as long as possible. In the context of preservation of self, Beard *et al.* (2011) highlight the importance of ageing in place for persons with dementia.

However, Cahill (2018) considered ten national dementia strategies and found that Ireland was among the countries whose strategies demonstrated a weak commitment to human-rights principles. Furthermore, the fact that the NDS neglects to adequately articulate how services and supports are to be redesigned in order to prioritise personalised care has been highlighted (Hennelly and O'Shea, 2017). This somewhat weakens the effectiveness of the strategy. In this regard, Hennelly and O'Shea (2017) point to the longstanding Irish approach in ageing policies of creating disconnect between stated policy and operation in practice.

National Carers' Strategy

Policy-makers are aware of the prevalence of informal care and there is widespread agreement of the need to support family carers (Ankri and Cassou, 2013, Lloyd, 2012). Published in 2012, the National Carers' Strategy (Department of Health, 2012) acknowledged from the outset the integral role of carers in achieving the policy objective of supporting older people as well as persons with disabilities to live in their own homes and communities for as long as possible. The strategy focused on care being provided in the community and defined a carer as someone who provides on-going and significant care to a person in the home, who is in need of such care owing to illness, disability or frailty. The strategy contained four national goals with corresponding specific objectives. The strategy made specific reference to older carers and carers with a disability, who may themselves be more vulnerable, particularly in terms of health and wellbeing.

Informal care and support is an essential component of community living and works in tandem with formal services and supports. This is undeniably true in the Irish context where family carers are called upon to provide the bulk of care hours for loved ones in the absence of adequate formal provision (Callan and O'Shea, 2015, Murphy *et al.*, 2015, Kamiya *et al.*, 2012). Indeed, research based on the Irish Longitudinal Study on Ageing (TILDA) revealed that almost 90% of caregiving for older adults in the community was unpaid and informal (Kamiya *et al.*, 2012). Furthermore, in respect of main carers, the majority were aged 50 and over, were spouses, and 70% were women. Indeed, TILDA data highlights the significance of the ‘older carer’ and that spousal older carers are predominantly women (Kamiya *et al.*, 2012).

Fulfilling a caring role can be an enriching and rewarding experience but it can also exert a toll on the carer to the detriment of their physical, psychological and emotional wellbeing (O'Sullivan *et al.*, 2017). Accordingly, adopting and implementing a comprehensive carers strategy was deemed necessary to support the vital contribution that carers make to supporting older persons and persons with disabilities to remain living in their own homes and communities. Supporting family carers with supplemental formal support is therefore of paramount importance and furthermore could reduce the demand for institutional services (Sigurdardottir *et al.*, 2012). However, in Ireland the level of generosity of support for family care has been found to be at a low-to-medium level (Eggers *et al.*, 2018).

While the aforementioned aspects of the Carers Strategy offered promise, Family Carers Ireland in their recent assessment, ‘Family Carers’ Scorecard’ (Family Carers Ireland, 2017), have found that only 18 of the 42 objectives have met acceptable progress levels. Furthermore, their assessment highlights the negative impact on the wellbeing of carers as a consequence of a lack of supports and in particular respite care. This impacts on the ability of carers to support their loved ones in the home and can lead to institutionalisation in formal residential settings. Tellingly, five of the objectives met with a ‘regressive score’, which meant that the issue had in fact deteriorated for carers in the lifetime of the carers’ strategy. These issues related to a lack of respite care, a lack of family consultation in relation to discharge from hospitals to home care, transport issues under the Disability Act 2005 and issues relating to the children and young people with caring responsibilities. The strategy may therefore be said to suffer from an implementation deficit (O'Sullivan *et al.*, 2017).

In Ireland, a significant proportion of carers are aged over 65 and this is increasing quite substantially (Hanly and Sheerin, 2017). However, it is important to note that existing and increasing reliance on informal care articulated through re-familialisation of care has a gendered dimension in that the caring responsibilities often fall disproportionally to female family members such as wives and daughters (Dahlberg *et al.*, 2018). Recent Irish research (Hughes and O'Sullivan, 2017) has also highlighted that caring responsibiliites often rest with women. Research involving five European countries also found that the bulk of caring resposibility in Ireland rests with women and attibuted this to a lack viable alternatives that either relieved some of the responsibility or adequately compensated them (Eggers *et al.*, 2018). This gendered aspect of care exists even amongst older persons themselves, as they are not exempt from caring responsibilities. Sigurdardottir *et al.* (2012) note that men tend to get more informal care from spouses, particularly in domestic tasks, but that this would not even necessarily be categorised as informal care.

In summary, although Irish social policy in ageing has evolved from the traditional dominance of family care to a more collaborative approach that recognises diversity and the roles of various actors, most importantly older persons themselves, as parties to social policy, issues persist that serve to hinder meaningful community living. Issues relating to implementation, resources and an overall apparent lack of joined-up thinking serve to impede meaningful improvement in the lives of older persons, including older persons with disabilities. Awareness of challenges and opportunities presented by Ireland's ageing population is evidenced in the recent joint policy statement on housing options (Department of Housing, Planning and Local Government & Department of Health, 2019). Forewords by both minsters to this statement reflect an appreciation of the heterogeneity of the older population and the need to support older people to live independent, included and meaningful lives in their own homes and communities, while cognisant of the continuum of support needs that exist. Pierse and O'Shea (O'Shea *et al.*, 2017) in the context of dementia, remark that exploration of the continuum of care in Ireland is still in early stages, but that there is much potential to expand budgets for home care before the point of saturation is reached and residential care becomes a fiscal choice. ALONE, a national organisation supporting older people to age at home, has also called for greater exploration of the continuum of housing (ALONE, 2018).

3.4.5 Disability Policy

Fitzgerald (2007) highlights the precarious position of persons with disabilities as one of the most at-risk groups for poverty in Ireland, and furthermore their risk of multidimensional social exclusion, with lower participation in domains such as education, employment and relationships. Although Gilleard and Higgs (2017) highlight that there is relatively little research on how late-life disability results in social exclusion, they cite Irish research (Cullinan *et al.*, 2013), which found that the most socially excluded were single pensioners with severe disability. This speaks to the life-course factors, such as personal social relationships, that impact on the experience of disability in older age. Fitzgerald (2007) contends that given the breadth of these issues, there must be an equally broad policy response.

Mirroring the reality in ageing policy, the Irish response to the needs of persons with disabilities was traditionally family-orientated with care also provided in large state institutions, often operated and administered by the Catholic Church.

This was an approach that Fitzgerald (2007, p.240) deemed "laissez-faire" whereby the state abdicated responsibility and denied the rights of persons with disabilities. A move towards specialisation in the 1960s reflected the assumption that persons with disabilities, particularly people with intellectual disabilities, had special needs. As a result, an industry grew as a response to disabled persons' perceived special needs (McCormack, 2004).

However, reflecting international trends, there have been shifts regarding the perception of persons with disabilities in Irish society and this has been articulated in policy responses (McConkey *et al.*, 2019). The social model of disability, which recognises the interaction between impairment and the societal response in the experience of disability, gained prominence in disability activism in the United Kingdom in the 1990s (Oliver, 1990) and the ripples of the disability rights movement were felt in Ireland. Quin and Redmond (2005) credit the concept of rights for persons with disabilities as being the catalyst for the shift in attention from individual inability to societal barriers. The Commission on the Status of People with Disabilities was established in 1993 for the purpose of advising the government on how persons with disabilities could experience their rights of participation in all aspects of life and to examine the adequacy of existing services and recommend legislative, policy and practice changes deemed necessary to ensure needs were met.

Following a lengthy and comprehensive consultative process with persons with disabilities, their family members and representative organisations, *A Strategy for Equality* (Commission on the Status of People with, 1996) was published. The report included some 402 recommendations, which served to highlight the major effort that was required to redress the shortcomings in disability policy (Dukelow and Considine, 2017). In the report overview, persons with disabilities were called "the neglected citizens of Ireland" subject to "out-dated social and economic policies" and while change in the form of the emergence of the social model was acknowledged, the charity model and piecemeal nature of change was lamented (Commission on the Status of People with Disabilities, 1996, p.4).

This increased focus on disability coincided with legislative efforts to tackle discrimination and unequal treatment including the Employment Act 1998, the Equal Status Act 2000 and the Equality act 2004 (Fitzgerald, 2007). A notable development that followed was the 2004 Disability Strategy, a framework for the participation in society of persons with disabilities based on the principles of mainstreaming, equality and inclusion, with legislative elements including the Disability Act 2005, the Education for Persons with Special Educational Needs Act, 2004 and the Citizens Information Act 2007 (Fitzgerald, 2007). However, many provisions of the Disability Act 2005 have not been enacted, such as the right for an Individual Assessment of Need (currently limited to children born after June 2002). Indeed, the Disability Act 2005 has been portrayed as a missed opportunity for disability rights and the status of persons with disabilities in Ireland (De Wispelaere and Walsh, 2007). Furthermore, the Personal Advocacy Service with statutory powers, provided for under the Citizens Information Act 2007, was deferred and a non-statutory National Advocacy Service established in its place (Dukelow and Considine, 2017). These restrictions have served to limit the effectiveness of the 2004 Disability Strategy.

The current National Disability Inclusion Strategy 2017–2021 (NDIS) (Department of Justice and Equality, 2017) is intended to provide greater support for persons with disabilities. While overall responsibility for implementation falls under the remit of the Department of Justice and Equality, the NDIS highlights disability as being a society-wide issue and the responsibility of every government minister, therefore advocating a cross-departmental approach, including among others, the Departments of Housing and Social Protection. The NDIS acknowledges the relationship between ageing and disability, highlighting that the likelihood of disability increases with age and that three of five people aged 60 and over have at least one chronic condition. The NDIS focus on eight key areas, the majority of which have relevance in the context of community living: equality and choice; joined up policies and public services; health and wellbeing; person-centred disability services; living in the community; and transport and accessible places.

In particular, the NDIS reasserts the commitment to transition persons with disabilities out of congregated settings and into homes in the community, with a stated aim to reduce the number of people living in congregated settings by one-third by 2021. In the realm of housing, the NDIS also commits to streamlining the housing adaptation grant schemes for persons with disabilities and older people. However, Senator John Dolan, CEO of the Disability Federation of Ireland has called the NDIS "at best a naive and half-hearted attempt at addressing the most serious issues facing the disability community", one of which he states to be the shortage of social housing (www.senatorjohndolan.ie).

3.4.6 Demarcation

In Ireland, ageing and disability supports and services are delivered though two distinct streams. This division along chronological lines is not altogether unusual and yet it is problematic, particularly for older persons with disabilities who straddle sectors and can be lost in the cracks. In Ireland, supports and services are provided through a mix of public, private and voluntary sources. The delineation in ageing and disability is starkly evident in the manner in which these services and supports are delivered to older people and persons with disabilities. Responsibility for ageing and disability services fall under two separate departments in the Health Service Executive (HSE), thereby categorising provision of services according to a person's chronological age (for further information see https://www.hse.ie). Arguably, this does not best serve the interests of older persons with disabilities in achieving goals such as meaningful community living. Love and Lynch (2018), in their consideration of human rights and older people, reflect that there are as many ways to be old as there are to be young and accordingly older people represent a diverse group comprising a similarly diverse mix of abilities and needs that do not always fit into neat chronological boxes. Support needs do not suddenly cease or alter dramatically on turning 65. Ageing and disability are dynamic processes and therefore demand dynamic responses.

State welfare supports are indicative of the chronological age distinctions that run through ageing and disability. There exist a number of standout ages when it comes to welfare payments. Illustrative examples of this include the medical card, qualification for which is assessed under different rules for those aged under and over 70. A further differential is made between those aged under 66 and those aged 66-70. The Disability Allowance is a means-tested social welfare payment. It is payable to people between the ages of 16 and 66 who have a disability that substantially restricts them from engaging in paid employment suitable for their age, qualifications and experience. Different rules have applied in the past for persons living in institutional care including residential homes and nursing homes. For instance, prior to 2007, the Disability Allowance was not payable to persons who lived in institutions where the costs were being paid for by the HSE other than in cases where the person had a pre-existing entitlement prior to entering residential care (welfare.ie). The State Pension (Contributory) is paid to people from the age of 66 subject to them meeting the requisite number of social insurance contributions with an automatic increase of €10 applied at age 80. Invalidity Pension is paid to people under the age of 66 who cannot work owing to disability or long-term illness. On turning 66, a recipient automatically transfers to the State Pension (Contributory) at the full rate.

3.5 Policy Issues and Responses

Refracted through the lens of equality and fairness, policies that directly or indirectly promote institutionalisation and dependency, and otherwise deprive older persons with disabilities of the support they require to maintain independence in the community, have been found wanting (Inclusion Ireland, 2018). Such shortcomings have highlighted the need for innovation in community living policies at the intersection of ageing and disability. Ireland is attempting to move away from restrictive and redundant policies and instead seek a more rights-based approach towards social care (McConkey *et al.*, 2019). As Bickenbach (2014) highlights, rights can determine policy goals, serving as a “moral compass”. As these efforts continue, it is clear that the right to community living is becoming an increasingly prominent policy issue, not least at the ageing/disability nexus. This has significant ramifications for social care actors including governmental departments and service providers. It also offers the potential to redress the inequities in community living policies currently experienced by older persons with disabilities.

3.5.1 Deinstitutionalisation

De-institutionalisation, understood as the closure of large scale institutions and the facilitation of persons with disabilities to live and participate in their communities, was partly motivated by civil rights movements in the US in the 1960s and 1970s (Wiesel and Bigby, 2015). De-institutionalisation may, therefore, be considered as a policy response borne out of a desire for justice and fairness for persons with disabilities and also the growth in human rights and advocacy (Tatlow-Golden *et al.*, 2014). It is indicative of a new paradigm that recognises that persons with disabilities are capable of making decisions and, furthermore, that these decisions should be respected and facilitated though empowerment and individualised supports (Bradley, 2013).

Research over many years has demonstrated that community-based services are superior to institutional models of service provision (Mansell, 2006). Furthermore, transition to community has been promoted as a means of increasing the participation, integration and engagement of persons with intellectual disabilities in society (King *et al.*, 2017). De-institutionalisation can improve the inclusion and wellbeing of persons with intellectual disabilities, as living in the community enhances personal relationships, access to services and self-determination (Owuor *et al.*, 2018). The latter is perhaps most significant from a rights-based perspective as it is choice and control that is most strikingly absent in many, although not all, institutional settings. This does not foster self-determination but rather creates a culture of dependency. Evidence suggests that community dwelling as opposed to institutional living delivers better outcomes such as greater social connectedness, an important component of successful ageing (McCausland *et al.*, 2016).

Ireland has begun the process of addressing the living arrangements of persons with disabilities, particularly intellectual disabilities (Owuor *et al.*, 2017), having a historically established practice of institutionalisation in common with many other countries (Watchman, 2018). Ireland's history of institutionalisation came to the fore in a 2011 review that gave rise to a policy of de-institutionalisation, which is the transitioning of people from institutional settings to homes in the community. The Health Service Executive (HSE) Report, *Time to Move on From Congregated Settings – a Strategy for Community Inclusion* (HSE, 2011) was adopted as a national policy and set forth a new strategy with the aim of supporting persons with disabilities to live independently and be included in the community. This policy is in keeping with the human rights approach epitomised in Article 19 of the CRPD. Congregated settings were defined in the report as residential settings housing ten or more persons with disabilities and approximately 4,000 people were identified as living in such settings in Ireland. These congregated settings were deemed to be incompatible with the promotion of rights, such as privacy, independence and dignity. Inclusion Ireland (2018) state that institutions are abusive environments, represent a breach of rights under the CRPD and offer outcomes inferior to community living. They reject institutionalised practices and call for community living arrangements.

However, the de-institutionalisation process has been slow. Annual targets set by the HSE to transition people into the community have never been met and Inclusion Ireland have highlighted that in 2015 and 2016 more individuals died (216) than moved into a home in the community (185) (Inclusion Ireland, 2017b). More recently, Inclusion Ireland (2018) have stated that of the 1,500 people to move out of large congregated settings, only approximately 10% have moved into their own homes, with the majority moving into what they view as smaller institutions and nursing homes. Others have, sadly, died. The impact of current housing shortages has had a bearing on the slow pace of de-congregation. The

National Housing Strategy for People with a Disability 2011-2016 (Department of the Environment, Community and Local Government, 2011) was developed to work in tandem with the 2011 congregated settings report and the has been extended to 2020 so as to continue to strive to address the housing needs of person with disabilities (ICSH, 2017). Furthermore, Housing and Disability Steering Groups were established in all local housing authorities in 2016 so as to adopt a coordinated approach to meeting the aforementioned housing needs of persons with disabilities within the established housing supply system (Department of Health, 2017).

Undoubtedly, the segregation in congregated settings of persons with disabilities, particularly intellectual disabilities, represents one of the greatest failings in Ireland's relationship with disability. This policy response to the needs of persons with disabilities was the antithesis of a rights-based approach and was predicated on misguided beliefs about the nature of ability, capability and, perhaps most importantly, personhood. Institutionalisation continues to be a feature of Irish disability policy, particularly for persons with intellectual disabilities. A recent study consisting of a random sample of 753 people, representing 8.9% of persons aged over 40 with an intellectual disability in Ireland, found that almost half (47.3%) lived in a congregated setting, a residence consisting of ten or more people (King *et al.*, 2017).

Older persons with disabilities, in the absence of viable alternatives, such as sufficient community-based services and supports, will continue to find themselves under threat of institutionalisation in nursing homes and other residential settings. Herring (2018) highlights issues that can occur in residential care such as the lack of dignity and privacy, infantilisation and neglect. In Ireland, protracted and systemic abuse has been revealed in both nursing homes (Leas Cross) (Phelan, 2014) and residential settings (Aras Attracta) (HSE, 2016a). As the number of persons ageing with intellectual disabilities continues to increase, factors such as health needs (McCarron *et al.*, 2017) and the loss of aged parents to continue a caring role, will be increasingly pertinent factors. This is not just an issue for persons with intellectual disabilities, as persons with physical disabilities are also being denied appropriate service and supports in the community. This is resulting in placement in residential settings, contrary to human rights principles of autonomy, dignity and independence.

Entry into residential care as an older person may be described as a major life event with negative consequences for social and emotional well-being (Stevens *et al.*, 2015). Stevens *et al.* (2015) conducted an intervention for older persons with functional impairments who were deemed at risk of nursing home placement in the US. Their community-based programme combined evidence-based interventions with formal home care services to support well-being and health and 12 months on from the start of the intervention, only 6% of the high-risk candidates had entered residential care. Furthermore, participants reported positive results, which demonstrated an improvement in health, well-being and quality of life. Such studies highlight that with the proper interventions, older persons with disabilities can continue to live and age well in the community. Not only is this better for the individual but also for the state as in many countries residential care subsumes a large proportion of the budget for older persons services. As an example, institutional care in Sweden in 2010 took two-thirds of the eldercare services budget (Schon *et al.*, 2016).

Research in the US found persons with disabilities had a greater degree of choice in their own homes or in smaller group home settings (Tichá *et al.*, 2012). A recent study that looked at the experiences of a group of people with intellectual disabilities who moved from a congregated setting to housing in the community revealed a largely positive experience. The participants in the study were all in middle or older age and had lived for a considerable time in institutional settings before the move to community. Overall, the participants in the study experienced increased freedom and independence as well as choice and control. They were happy to have moved into the community, although admittedly for some social integration had proven more difficult. This could perhaps be explained by age and highlighted the need to tailor supports to an individual's specific needs. The move had led to more "individualised possibilities" and allowed participants to realise individual goals (Sheerin *et al.*, 2015). This highlights that independence can be encouraged and developed with the appropriate supports.

Even when considering variances of community living, evidence suggests that a significant proportion of persons with intellectual disabilities living in group homes are capable of greater levels of independence in more supported living arrangements and do not require such high levels of staff support (Bigby *et al.*, 2017) Community living represents an opportunity to develop the life skills of the person and to afford them the opportunity and support to maximise their strengths and enhance their quality of life. It has been demonstrated that following transition from institutional settings to the community, persons with intellectual disabilities experience a better quality of life and marked improvements in areas such as social relationships, choice and control, community inclusion and participation (Tatlow-Golden *et al.*, 2014). Indeed, a recent study found that older adults with intellectual disabilities who were living independently, with family or in group homes (living in the community with support from paid staff) performed better in all activities of daily living than persons living in the institutional settings (King *et al.*, 2017). Evidence further suggests that there is greater potential for choice and autonomy in community settings (King *et al.*, 2017) and that choice and control is very important to persons with intellectual disabilities (García Iriarte *et al.*, 2014).

3.5.2 Personalisation

Traditionally, persons with disabilities have been viewed as care recipients rather than directors of their supports. Such thinking is increasingly regarded as being incompatible with a rights-based approach that recognises and values self-determination, person-centeredness and autonomy (Dowling *et al.*, 2006). There has been a shift from a passive welfare model to a more dynamic approach that recognises persons with disabilities as the directors of their own lives and individualised funding is central to this new approach (Keogh and Quinn, 2018).

Love and Lynch (2018), in their consideration of personalisation in the Scottish context of older people's services, note that its intended purpose is to reconceptualise older people as engaged rather than passive recipients of care.

Currently, services for persons with disabilities in Ireland are under the responsibility of the Health Service Executive (HSE) under the remit of the Department of Health. The HSE, and the service providers that it funds, administer services in nine regional areas called Community Healthcare organisations (CHOs). Where the HSE is unable to provide the required services, they are provided by HSE funded local, voluntary and non-statutory organisations (Keogh and Quinn, 2018). This has resulted in uneven distribution and unmet need. These historic arrangements also preclude choice for the client in service provider (Genet *et al.*, 2012). These issues have been highlighted in a recent government committee report on the future of healthcare as being both an inequitable situation for persons with disabilities and an inefficient use of public funds (Houses of the Oireachtas, 2017). There are insufficient personal assistance hours, a prerequisite for many persons with disabilities to lead an independent and autonomous life in the community. The personal assistance hours that are provided are increasingly only sufficient for personal care and not for community inclusion. Furthermore, in 2017, there were approximately 7,500 persons with disabilities on social housing waiting lists in Ireland (RTE News, 2017). The National Disability Authority (NDA) in their submission on social housing (2014) highlighted that owing to life-course factors, persons with disabilities are more likely to rely on social housing, 12.8% compared to 8.3% of the general public.

Persons with disabilities in Ireland have traditionally received the services they need through a service provider. This process operates on the basis that an amount is allocated to each service provider to meet the needs of the persons with disabilities who use that particular service. Therefore resources are bundled and not allocated to each service user on the basis of individual need (Fitzgerald, 2012). This continues to be the dominant model of service provision in Ireland (Fleming *et al.*, 2017). However, this model of provision does not allow for much self-direction or indeed service user consultation. International influences such as the CRPD have stimulated change on the domestic policy landscape with a move towards more choice and options for persons with disabilities to live lives of their own choosing in their communities (McConkey *et al.*, 2019). Individualised funding is one means of facilitating this new direction. From a human rights perspective, individualised funding options represent a better option for persons with disabilities, given that they are underpinned by human rights and social justice ideologies (Hamilton *et al.*, 2017), allowing for a greater degree of choice and control and arguably delivering better outcomes for the person (Fleming, 2016). Love and Lynch (2018) see personalisation as potentially affording older people more choice and tailored supports by moving beyond the traditional 'one-size-fits-all' approach.

The main benefit of personal budgets is seen as laying in the degree of independence and self-determination that they afford the individual (Carr, 2010, Stalker *et al.*, 2000). This is important from a rights-based perspective. Community living is intrinsically linked to individualised funding as exemplified by the personal budgets model. Indeed, individualised funding has its roots in the Independent Living Movement as a means by which person with disabilities could direct their own lives through the hiring of personal assistants (Fleming et al, 2016). Knowing that persons with disabilities favour living in the community, developing a personalised budget model is an important step in transforming the service provision landscape.

In order to realise the right to live independently and be included in the community, as set out in Article 19 of the CPRD, persons with disabilities must be afforded access to necessary services. Such services and supports will naturally vary depending on the particular and fluctuating needs of the individual, of which older age will also be a factor. Research conducted on behalf of the National Disability Authority on community living found that the meaning of independent living changed depending on life stages (Weafer, 2010). Younger people with disabilities may be adept at managing without the need to engage with services. However, they found that their needs and circumstances changed when they entered older age, however by that stage they were ‘out of the system’ so to speak and therefore found it difficult to access the disability services that they needed. Giving control over the acquisition of these services to the individual is theoretically intended to ensure that the best services can be sourced and obtained. These services may well be obtained from the traditional service providers but they may also be sourced from mainstream services in the community. Making informed decisions is a fundamental element of personalisation. Information regarding options and implications is required and this information should be personalised and trustworthy (Baxter and Glendinning, 2011).

This could have many positive benefits, not least economic, and undoubtedly arguments of neo-liberalism are a factor in this on-going service provision debate. It is necessary to be mindful of the climate of public expenditure cuts to services and the precarious situation that many persons with disabilities find themselves in. The period 2009 to 2016 saw a reduction of 7% in gross spending on disability services, despite the population requiring these services increasing (NDA, 2018). Personalised budgets are a new concept in Ireland and the extent to which they will transform the lived reality for persons with disabilities is untested. However, a recent study involving interviews with participants engaged in individualised funding initiatives in Ireland found that on the whole the individuals were pleased with the increased independence, confidence, empowerment and control that the individualised funding gave them (Fleming *et al.*, 2016).

Essentially, the goal of individualised funding models, such as personal budgets, is to afford persons with disabilities more control in obtaining the services that meet their particular and individual need rather than a generic suite of services. This could help make community living a reality for persons with disabilities, affording them greater control over the services and supports they require to live inclusive lives in the community. In devolving funding to the individual, control is also transferred. This is significant from a right perspective as choice and control allows for the development of the innate capabilities of the individual. The tools for independent living and community inclusion could be carried on into older age, thus reducing the likelihood of residential long-term care. Perhaps most importantly, by bringing persons with disabilities into the community as consumers of services, the community for its part may become more inclusive and responsive to diversity. Although community living means different things depending on multiple factors, not least age and social circumstances, the central principle remains the same and that is to facilitate choice and control, uphold rights and provide supports and services sufficient to live the best life possible (Weafer, 2010).

The issue of individualised funding for persons with disabilities has also become a topical issue that has attracted governmental attention. The 2016 Programme for Partnership Government (Department of the Taoiseach, 2016) emphasised empowering persons with disabilities to lead independent lives with greater independence in relation to accessing services of their choosing and tailoring supports to their particular needs. Furthermore, there was an expressed commitment to introduce personalised budgets in recognition of the fact that they provide the person with more independence, choice and control. They also allow the individual to seek the services that best meet their needs and this may be from sources other that the traditional service providers.

On foot of this commitment, a Taskforce on Personalised Budgets was formed in late 2016 comprising of a Strategy Group and an Advisory & Consultative Group. The remit of the Taskforce was to make recommendations for the design and implementation of a model of personal budgets for persons with disabilities requiring HSE-funded personal social services and supports, such as personal assistance and day services (Department of Health, 2017). In 2018, the Taskforce published its report, *Towards Personalised Budgets for People with a Disability in Ireland* (Department of Health, 2018). The report makes 18 recommendations and advocates a 5-stage model for personalised budgets with a pre-stage assessment of need. The recommendations propose a national framework for personalised budgets, which would be used to support daily living activities and community participation including personal assistant or home care support. The lack of personalised funding options in Ireland currently limits persons with disabilities, including older people, in exercising choice in how they live their lives and obtain the services and supports they need in the community. This is therefore also a barrier to effective community living. Fitzgerald (2012) highlights a need to 'follow the money' and contends that the current model of disability services in Ireland delivers poor value for money. Fitzgerald further highlights that the current system affords persons with disabilities little say over the services they receive and no control over the budgets paid over in their names. Arguably there is a need to do things differently and the personal budget model is one avenue of exploration.

3.5.3 Home Care

Home care in Ireland is typically understood as home help services, which include cleaning, cooking and other light household tasks that a person is unable to do themselves due to old age or disability. The scope of home help has subsequently developed to include more personal care assistance such as support with personal hygiene, washing, and dressing also (Kiersey and Coleman, 2017). As previously noted, most older people express a desire to remain living in their own homes in the community (Donnelly *et al.*, 2016). This is also reflected in the living arrangements of the overwhelming majority of older Irish people who live in their homes, with formal or informal care (Murphy *et al.*, 2015).

Home care is a means of facilitating independence and supports the preference of older people with disabilities to remain in their own homes and communities (Rostgaard *et al.*, 2012). Over 50,000 people are in receipt of formal home care services in Ireland (Timoney, 2018). However, issues beset home care including under-funding despite significant increase in demand and a lack of statutory entitlement to guarantee access (Hanly and Sheerin, 2017, Donnelly *et al.*, 2016, Gannon and Davin, 2010). The lack of a national regulatory system has led to disparity between public and private providers of home care services with implications for standards and fees (Genet *et al.*, 2012, Timonen *et al.*, 2012a). Furthermore, the absence of a national eligibility and entitlement criteria has given much leeway to private and non-profit providers (Kiersey and Coleman, 2017).

Currently, there is a statutory right to residential care by virtue of the Nursing Home Support Scheme, otherwise known as "Fair Deal" scheme. The scheme was established in 2009 under legislation (Nursing Home Support Scheme Act, 2009). The scheme, administered by the HSE, operates on the basis that persons assessed as requiring long-term residential care make a contribution based on their means and can access financial support from the State for the balance (for more detailed information see https://assets.gov.ie/NHSS.pdf). One of the strongest criticisms of the scheme is that it cannot be used to pay for home care and accordingly has been to the detriment of community-based services, consequentially bringing people to residential care prematurely (Timoney, 2018). In light of this criticism, and against a backdrop of increased media attention and public pressure, Ireland is attempting to address inadequacies in the provision of long-term care.

A public consultation process to explore the viability of a state supported home care scheme was launched in 2017 (Department of Health, 2017). The government has committed to introducing an equitable and regulated statutory home care scheme, but has also stressed the complexity of this undertaking and the decisions that are yet to be made regarding its form (Department of Housing, Planning and Local Government & Department of Health, 2019). Nevertheless, this process is a step in the right direction from a rights-based perspective, as placing home care on a regulated footing akin to residential care would undoubtedly benefit older persons with disabilities seeking to remain living in the community by increasing their viable options and alternatives.

Shortcomings in home care services and supports have also come to the fore in the debate around community-based services and supports. At present, Ireland does not have a statutory entitlement to home care, and home-care packages, which offer tailored support to persons at risk of long-term residential care, are allocated on foot of an administrative system characterised by unmet need and uneven access and provision (Donnelly *et al.*, 2017, Donnelly *et al.*, 2016, Timonen *et al.*, 2012a). This situation further increases the likelihood of older persons with disabilities having to enter long-term residential care in the absence of sufficient home care supports. Evidence presented to the government committee on the future of healthcare has highlighted the potential for increased community-based interventions, such as physiotherapy and house adaptations, at a relatively low cost to the state (Houses of the Oireachtas, 2017).

Furthermore, although the policy of the state has long been stated to support older people to remain living in their own homes with the required supports for as long as possible (Timonen *et al.*, 2012a), there is a bias towards residential care in that the only statutory right to support for long-term care applies to residential care by virtue of the Nursing Home Support Scheme (NHSS) (Boutaugh and Lawrence, 2015, Wren *et al.*, 2012). This is reflected in funding, as in 2017 €940 million was allocated to the NHSS whereas €403 million was allocated to home care provision, although the latter supports over double the amount of people (Houses of the Oireachtas, 2017). This imbalance between spending on home care versus residential care has long been a criticism of government policy on long term care and supports (Aspell *et al.*, 2019). Such residential bias is inconsistent with a rights-based approach that prioritises the right to live an independent and included life in the community and also contradicts stated policy (Hanly and Sheerin, 2017).

In order to remain living in the community, many persons with disabilities and older people rely heavily on informal care, usually provided by family members (Weaver and Roberto, 2015). In the case of persons with intellectual disabilities, it has been highlighted that the proportion that live in their family home decreases substantially as the person ages (Bigby, 2010). Therefore, the risk of institutional care increases with age for this group. Persons with intellectual disabilities are less likely to have the support of spouses and children to assume a caregiving role and instead rely significantly on parents and siblings, with the latter often accepting the caregiving mantle from ageing parents (Coyle and Mutchler, 2017). As parents age, it is increasingly likely that they will come to experience disability themselves and be unlikely to maintain their caregiving role (Shaw *et al.*, 2011). Scant support is afforded to family carers, who are said to assume significant responsibilities with potential for loneliness, isolation, stress and depression (Chadwick *et al.*, 2013).

While Ireland launched a National Carers' Strategy in 2012, Family Carers Ireland's 2017 'scorecard' of the strategy identified only one of the 42 actions as having been implemented in full and as making a real difference in the lives of family carers (Family Carers Ireland, 2017). Therefore there exists the potential for carer burnout and abuse in some circumstances. This further impacts on the rights of the older person to live in the community. However, in the absence of sufficient formal services and supports in the community, this practice of overreliance on family carers will continue. Although many family members express satisfaction with their caring role, especially where there is companionship, affection and reciprocity (Stoltz *et al.*, 2004), the relationship is oftentimes an unequal one, born out of necessity in the absence of sufficient formal supports. From a rights-based perspective, this is not an equitable situation and there is potential for abusive behaviours to develop (Lafferty *et al.*, 2016, Naughton *et al.*, 2011, Cooper *et al.*, 2008).

Undoubtedly issues beset home care services and the impact of public funding cuts is also felt. There is no statutory entitlement to home care services to support people to remain living in their own homes. The lack of a national regulatory system has led to disparity between public and private providers of home care services with implications for standards and fees. Furthermore, the absence of a national eligibility and entitlement criteria has given much leeway to private and non-profit providers (Kiersey and Coleman, 2017). The non-statutory position of home care in Ireland serves as a barrier to effective community living options for older persons with disabilities.

3.6 Chapter Summary

Against a backdrop of ageing and disability trends, this chapter has provided an overview of ageing and disability policy in Ireland, using illustrative examples. Supporting older people and persons with disabilities to live and age in the community is a policy objective in both the ageing and the disability sectors. This is evidenced by the various policy documents that have been drafted over the last number of years that have referenced this objective (e.g. National Positive Ageing Strategy, National Dementia Strategy, National Disability Inclusion Strategy 2017–2021,(Department of Justice and Equality, 2017). However, there has not been much coordination of efforts in either sector. This begs the question of whether merit is to be found in exploring a more unified approach in pursuance of a common policy objective such as community living.

Community living potentially offers the most in terms of commonality and therefore represents a place to conduct research to address the silo-specific nature of policy responses. This research seeks to understand what community living means to the group of people who are both older and disabled as a means of exploring this potential. Older persons with disabilities represent a growing group who straddle ageing and disability and for whom policy responses must be cognisant of their intersectional characteristics (Heller, 2019; Bickenbach *et al.*, 2012). According to the research evidence, older people and persons with disabilities share a desire to live independent and included lives in the community. However, both groups can experience challenges in realising this goal. Both groups are exposed to inadequate community-based supports and services and models of support that are inflexible and constrained by chronological eligibility criteria (Rickli, 2016; Breitenbach, 2001).

Reflecting the particular characteristics of Ireland's welfare state, shortcomings in current policies that have led to institutionalisation, insufficient community-based supports and the absence of service-user direction and general consultation, appear to have hindered the progress of community living. In light of a growing awareness of human rights and the recognition that older persons with disabilities have a right to be supported to live and be included in the community, Ireland is seeking to redress these shortcomings. The extent to which Irish social policy, directly and indirectly relating to community living, is undergoing reform has also been considered. Developments in the realm of de-institutionalisation, personalised budgets and home care have been identified.

Along with Chapter 2, this chapter has sought to provide a framework for the empirical study. The next chapter documents the methodological approach and methods employed for the empirical study. Exploring the lived experience of community living for the group that occupy the ambiguous space straddling both ageing and disability is necessary in order to address gaps in the understanding of community living and to capture their underrepresented voice (Westwood and Carey, 2018). Furthermore, eliciting the perspective of ageing and disability stakeholders allows for a more subjective understanding of the ageing/disability nexus and the policy motivations in both sectors.

Chapter Four
Research Methodology

4.1 Introduction

This research study explored community living for older persons with disabilities. The research question addressed how community living is conceptualised and experienced at the ageing/disability nexus. Both this aim and research question frames the methodological approach and the decisions made about study design and methods. As explored in Chapter Two, community living was construed for this group as comprising constituent elements of independent living, ageing in place and community interaction. The rationale for pursuing interdisciplinary research in ageing and disability on the topic of community living was also provided. The desire to capture 'voice' and 'insight' from older persons with disabilities and stakeholders respectively was also noted at an early stage in this project.

This chapter begins by outlining the methodology, which includes the research paradigm and positionality and the methodological approach. The chapter will then focus on study sampling and participant recruitment. This will include a discussion on the rationale for the chosen methodology. The methodology and study design reflect both the purpose of the research study and the specific characteristics of the group of people that the study focuses on. This chapter also expands on the study methods from data collection through to data analysis. It details ethical considerations and researcher reflexivity. The chapter concludes with an overall summary, laying the foundation for the findings chapters that follow.

4.2 Methodology

4.2.1 Researcher Positionality

The researcher's philosophical worldview has a direct bearing on the approach adopted in the research study and encompasses the researcher's ontological and epistemological position. Ontology and epistemology shape how the researcher views knowledge and their own position in relation to this knowledge (Flick, 2018). Once this is established, methodology is the approach and method the tools that the researcher takes to acquire this knowledge. Creswell (2014) highlights the interconnection between the researcher's philosophical worldview, the research design that best fits this worldview, and the research methods that translate the approach into practice. It is essential that all of these elements are considered and made explicit at the outset of the research study.

The research paradigm is important as it dictates what phenomenon should be studied, how research should be done and how results are interpreted (Bryman, 2001). Creswell (2014) favours the term 'worldview' and interprets it as the researcher's philosophical orientation that they bring to their research study. Three particular worldviews are widely known and discussed – positivism, pragmatism and constructivism. Broadly speaking, positivists believe that there is a single measurable and objective reality and most often employ quantitative methods to measure this reality (Ritchie *et al.*, 2013). Indeed, Bryman (2001) defines positivism as an epistemological position whereby methods of the natural sciences are used in the study of social reality. Positivism, therefore, adheres to the belief that knowledge should be quantifiable and also emphasises the independence of the researcher from the study. Pragmatists believe that reality is constantly renegotiated and debated. Researchers adhering to a pragmatic worldview focus on the research problem rather than specific methods and utilise the approaches that best help them understand the problem. This position lends itself well to mixed-methods research (Creswell, 2014). Constructivists hold that individuals seek understanding of their world and that these meanings are many and varied. Constructivists believe that there is no single truth and rather reality is created and must be interpreted, with qualitative methods most commonly used to interpret such multiple realities (Creswell, 2014)

Constructivism

This study adopts a constructivist research paradigm or worldview. Within this paradigm, ontologically, the position is that social phenomena within the social world are ideas constructed by the social actors involved. These ideas are constantly reviewed and reworked through a process of social interaction and reflection (Matthews and Ross, 2010). Epistemologically, constructivism is linked to the theoretical perspective of interpretivism (Creswell, 2014). Constructivist or interpretive research holds that reality is a social construction and the role of the researcher is to find meaning in the multiple social constructions that exist. Creswell (2009, 2014) states that researchers adhering to constructivism hold assumptions that individuals seek meaning in the world in which they live and that these individuals develop subjective meanings based on experience. The goal of the research is, therefore, to rely first and foremost on the individual's view of the topic being researched. Furthermore, researchers recognise their own part in the discovery of knowledge and the role that their backgrounds and experiences play in shaping their interpretation.

This research study explores the conceptualisation and experience of community living at the ageing/disability nexus. From the outset, I acknowledged my belief that community living could be experienced in different ways depending on multiple factors, including an individual's life-course experiences. In seeking to explore this topic, I recognised the importance of discovering these experiences from the personal accounts of older persons living with disabilities in the community. I also recognised that my background in law meant that I was motivated by a desire to pursue social justice for marginalised groups in society, such as older people and persons with disabilities. Furthermore, having personal family experience of disability and community living issues meant that I also held certain assumptions about how society should respond to these issues while adhering to principles of equality and fairness.

4.2.2 Methodological Approach and Design

Methodology refers to the manner in which the phenomenon studied is approached and incorporates consideration of the research question and the nature of the data that is to be collected to address those questions (Matthews and Ross, 2010). As this study was underpinned by a constructivist approach, an empirical study adopting a qualitative design was chosen. Flick *et al.* (2004) refer to qualitative research as claiming to describe life-worlds from the perspective of the participants and that in so doing a better understanding of social realities is sought. A qualitative design best suited the objectives of the research study. Furthermore, it was compatible with my own experience as a qualified lawyer trained in acquiring information through the medium of interview.

Having chosen a qualitative design, a number of methodological approaches were possible, warranting consideration and acceptance/rejection. Given the desire to capture lived experiences of older persons with disabilities and stakeholder perspectives, on this topic, the empirical study consisted of two phases of data collection, with each serving a distinct purposes – ascribing meaning and gleaning insight. The methodological approaches were reflective of these distinct purposes.

4.2.3 Phase One – Constructivist Grounded Theory

Phase One of the study involved interviews with older people with disabilities who were living in the community. The constructivist/interpretive perspective outlined above influenced this study. I was conscious of my role as a researcher in discovering meaning and multiple realities through qualitative research methods. Consequently, a grounded theory study adopting a constructivist approach was chosen for this research study (Charmaz, 2014). While adhering to many of the principles of grounded theory, this approach differs in some significant ways. In order to rationalise my choice of a constructivist approach to a grounded theory study, it is necessary to first chart the development of grounded theory and its various departures. The fundamental principles and processes that are common to all grounded theory studies, constant comparative analysis, theoretical sampling and theoretical saturation (Hood, 2007) are also discussed.

While Bryman (2016) cites grounded theory as the most widely used framework for analysing qualitative data, he also acknowledges that it is a complex theory to define definitively. Timonen *et al.* (2018) remark that is often misunderstood and Hood (2007) also contends that the proliferation of 'grounded theory' studies that are not always recognisable as such threatens the unique power of the method. In classic grounded theory, as developed by Glaser and Strauss (1967), the researcher is detached and objective, and a positivist approach is followed. In this way, an attempt was made to place qualitative research methods on a similar footing to quantitative approaches. This has ramifications in areas such as the literature review, as in classic grounded theory it is argued that it impacts on the ability of the researcher to maintain objectivity.

Strauss and Corbin (1990) developed this further by acknowledging that knowledge is created through action and interaction. They appreciated that the literature could be used as a means of sensitising the researcher to the data. Charmaz's (Charmaz, 2014, Charmaz, 2000) contribution has been the development of constructivist grounded theory, which argues that the researcher is a co-constructor of the research process and outcome (Ward *et al.*, 2015). In this approach, it is accepted that the researcher will already have some knowledge of the area that is being studied and that, through transparency and sensitising concepts, the validity of the research can be supported. As a result, reflexivity on the part of the researcher represents a central tenet of constructivist grounded theory.

Charmaz (2017) refers to her interpretation of grounded theory as a "contemporary revision", which while adhering to common principles differs for its relativist epistemology, acknowledgement of both researcher and participant in the research process, and multiple standpoints and realities. It adopts a reflexive stance as regards the researcher's background and values and relationship with the participants and situating the research within the conditions of its production. Constructivist grounded theory is mindful of the language, meaning and action of both the researcher and the participants.

Constructivist grounded theory offers a flexible and coherent approach for data collection and analysis. It is a means by which the researcher may explain the behaviour of the participants in their social world in the context of the research phenomenon. It ensures that the researcher is constantly engaged with the data and emerging analysis and, thus, helps the researcher to conceptualise what is happening in the data (Charmaz, 2017). Furthermore, as a method it facilitates the researcher's ability to explore and theorise social life. It strengthens the researcher's analytical skills and develops them towards theory construction (Charmaz, 2015).

Grounded theory is not so much a theory as an approach to generation of theory from data. As a consequence, it is concepts rather than theory that are most often generated through this particular method (Bryman, 2016). Timonen *et al.* (2018) also emphasise that "fully-fledged" theory does not always result (p.8) and that the most frequent outcome is "greater conceptual clarity, or a conceptual framework" (p.4). However, for a study to fit within the generations of grounded theory, some fundamentals must exist that adhere to the common principles of grounded theory approaches: it is an iterative process that employs purposive and theoretical sampling; the data itself gives rise to concepts and categories; theoretical development is advanced through data collection and analysis; the data is constantly and comparatively analysed; and theoretical density should be reached (Hutchison *et al.*, 2010). Hood (2007) refers to the fundamental processes of theoretical sampling, constant comparative analysis and theoretical saturation as the “Troublesome Trinity” (p.164).

4.2.4 Phase Two – A Flexible Approach

As Phase Two of the research study sought to gain insight through interviews with targeted policy stakeholders across a wide spectrum of the disability and ageing sectors, the methodological approach did not necessitate an interpretive stance. Rather, the stakeholder interviews were intended to complement the community interviews with older people living with disabilities and contextualise, from the perspective of policy and practice, emergent research findings. Accordingly, a more flexible approach was employed with regard to data collection and the methodology chosen for data analysis. Thematic analysis (Braun and Clarke, 2006) was chosen for this phase and will be expanded upon in the data analysis section of this chapter.

4.2.5 Study Setting

For Phase One, the study setting was Galway City and County in the West of Ireland, which has an overall population of 258,058 (Central Statistics Office, 2016). Galway City is a small university city with a population of 79,504 (Central Statistics Office, 2016). Together this allowed for the capturing of rural and urban diversity, different service infrastructures and meaning. Phase Two of the study comprised of stakeholder interviews and was not limited to any geographical area. Stakeholders from Ireland, Europe and North America were approached to participate in the study, allowing for a broad range of standpoints to be captured in the study.

4.3 Study Sampling and Participants

4.3.1 Study Sampling

In a study such as this, sampling is important in order to obtain information that addresses the aim of the study and the research question. Purposive sampling, a non-probability based sample often associated with small in-depth studies of this kind, was chosen as it allows for the in-depth understanding of the phenomenon being researched (Patton, 2015). In this form of sampling, participants are chosen, not because they are in some way statistically representative of the population they belong to, but rather for their characteristics and experiences that will illuminate the research topic and enable the researcher to explore the research questions (Matthews and Ross, 2010). Purposive sampling places the research questions at the heart of sampling considerations (Bryman, 2016).

In this study, a particular form of purposive sampling known as theoretical sampling was employed (Bryman, 2016). Theoretical sampling was utilised as a means of seeking further data from participants in order to test the emergent themes from the data. Theoretical sampling is defined by Glaser (1967) as a process of data collection for generating theory whereby the researcher jointly collects, codes and analyses the data in order to determine what data to collect next and from where so as to develop the theory as it emerges. This continues until theoretical saturation is reached and theoretical understanding has been achieved (Bryman, 2016). Theoretical saturation is reached when new data no longer adds to theoretical understanding and, therefore, further data collection is deemed to be unnecessary (Charmaz, 2006).

Researchers seek to make their findings credible and justifiable and this is directly related to the selection criteria applied to the sample (Denscombe, 2002). A number of decisions with regard to the inclusion criteria were justified with respect to the aims of the study, the participant population and the research question. For Phase One, a sample was achieved by adherence to inclusion criteria based on the characteristics summarised in Table 4.1., *Phase One Inclusion Criteria*.

Table 4.1: Phase One Inclusion Criteria

Age	50 and over
Gender	Female or male
Disability	Physical/sensory/intellectual/cognitive disability
Residential Location	Community residing

Age:

Reflecting age thresholds used for similar studies on these population groups in the international literature (Evenhuis *et al.*, 2012, Dew *et al.*, 2006, Freedman and Martin, 1998), age 50 was chosen as the minimum age threshold for participants in view of the aims of the study. By setting this as the minimum age threshold for participants, it was envisaged that a wide range of ages and associated life experiences would be captured in the study. Such a wide spectrum of experience was expected to add to the richness of the data collected. A further consideration in choosing the lower age threshold of 50 was the fact that some people with intellectual disabilities may experience age-related issues earlier than the general population (White and Mackenzie, 2015, McCarron *et al.*, 2013). An example of this is the higher rate of earlier onset musculoskeletal and sensory disorders as well as dementia associated with Down syndrome.

Disability:

The interpretation of disability found in the CRPD is utilised in this study. The CRPD does not define disability, but rather recognises it as an "evolving concept" that "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (United Nations, 2006, Preamble). Furthermore, the CRPD recognises that persons with disabilities "include people who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". Disability identity is complex and in this study an important consideration was when older persons with disabilities actually consider themselves to be such (Thurman and Harrison, 2019). Allowing participants to self-identify as an older person with a disability based on the inclusion criteria, as set out in the study information sheet was a more inclusive, fluid and encompassing approach.

Residential Location:

Participants were recruited from community rather than institutional settings. The decision to exclude persons living in institutional settings, such as residential care homes and nursing homes, was based on a number of persuasive factors. I took the view that people living in residential settings, including people who may have never experienced community living, might be constrained by their particular circumstances and express a certain bias towards 'what is' as opposed to 'what can be'. In other words, as the main research question focused on experiences of community living, I felt, on balance, that people actually experiencing the realities and challenges of living in the community with a disability were best placed to offer the requisite insight on this research topic. I also felt that the exploration of community living for residents of institutional settings would warrant, and indeed deserve a focused research study.

4.3.2 Participant Recruitment and Profiles

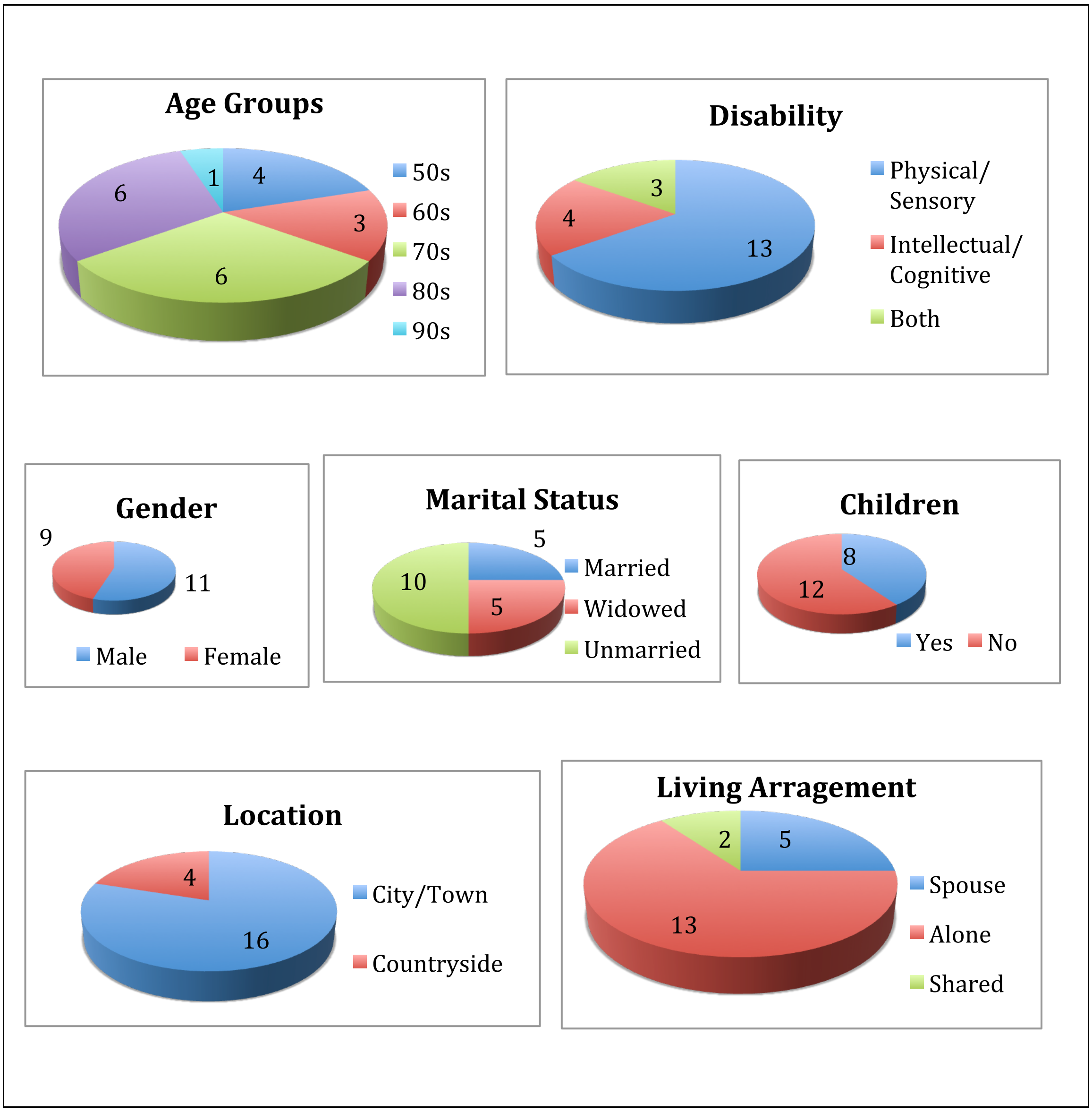
In qualitative research, especially in studies that follow a grounded theory tradition, there is no universal consensus on the appropriate sample size. Bryman (2016) acknowledges that establishing sample size at the outset of a research study is extremely difficult given that it is impossible to determine how many interviews may be required before theoretical saturation is achieved. Indeed, experienced researchers offer diverse recommendations in terms of sampling and recruitment (Baker and Edwards, 2012). Recruitment is related to many factors, not least to such pragmatic issues as the time and resources available and access to participants and their willingness to participate (Matthews and Ross, 2010). For Phase One of the study, involving older people with disabilities, it was envisaged that approximately 16-20 interviews would generate sufficient data to achieve theoretical saturation. However, it was also important to ensure a wide range of individuals would be recruited to capture narratives that would respond to the research question. In order to reach such a wide range of participants, a number of avenues were explored for recruitment.

Contact was made with a number of ageing and disability organisations at local and national level by email and telephone. However, not only was the initial response slow, necessitating numerous follow-up communications, but the generated pool of potential participants was limited, with many nominated people failing to meet the study's inclusion criteria (summarised in Table 4.1). Arising from this difficulty, I devised alternative recruitment strategies. I made personal contact with a number of local organisations that offered day services for older people in the community. In order to develop a relationship with the organisations' personnel, I spent time in the organisations and in so doing developed a rapport with the staff and service users. This allowed the service users to become familiar with me and, in time, to volunteer to participate in the empirical study. Ellard-Gray *et al.* (2015) highlight the value, where possible, of building rapport with potential participants from marginalized groups before attempts are made to recruit them into the research study. Furthermore, they acknowledge that such involvement in the particular community of the potential participants, and trust-building that accompanies it, takes time.

Alongside direct recruitment of participants from community organisations, snowball-sampling techniques were also used. This approach involves asking members of an initial sample to identify other people who they know and who share similar characteristics to them. The researcher then contacts the nominated individuals to seek their consent to participate in the project (Matthews and Ross, 2010). Snowball sampling was fruitful in that several participants recruited through community organisations identified other people in their networks who I was then able to contact in order to assess their eligibility and willingness to take part in the study.

As outlined in section 4.3.1, Phase One of the study sought to generate a purposive sample of older people with disabilities, with participants recruited in terms of the insights they could offer on the experience of community living. Diversity was sought in respect of gender, age, socio-economic status, living arrangement, location and disability. In all, 20 people were recruited to Phase One of the study. Figure 4.1 provides a breakdown of the study sample (Phase One). Appendix A sets out a further breakdown of the participant profiles.

Figure 4.1: **Breakdown of Study Sample Phase One**



Phase Two of the research study sought to gain broad policy insight from a cross-section of policy and opinion makers from the ageing and disability sectors at national and international level. The potential participants needed to have experience in ageing and/or disability and be able to offer their perspective on the ageing/disability nexus with a particular focus on the life course and community living. A sample size of 8-12 was deemed appropriate in order to meet this objective.

Recruitment was not narrowed to a particular geographical area as a wide spectrum of views was sought from a diverse range of stakeholders. Alongside stakeholders from Ireland, international stakeholders were recruited from other European countries and from North America. A series of research visits to various European countries were used not only to present emerging research findings to high-level stakeholders but also as a means of recruiting stakeholders to the study.

For Phase Two, I succeeded in recruiting a diverse range of stakeholders from the ageing and disability sectors as well as policymakers. In total, 9 interviews were conducted during the period June 2017 to May 2018. The participants came from a variety of organisations including representative organisations of older persons and persons with disabilities. Stakeholders had expertise in policy formation, advocacy, and service provision. Table 6.1 in Chapter 6 provides a breakdown of participant profiles. Stakeholders were highly qualified in their areas of expertise and had considerable understanding of issues relating to the research question of how community living is conceptualised at the ageing/disability nexus and ancillary questions pertaining to the life course and policy demarcations. They were able to give insight though contributing their perspective and that on their representative organisations to the topic of community living and issues relating to ageing and disability policy approaches.

4.4 Ethical Considerations

Ethics is of paramount importance in any research study that deals with human participants. In viewing qualitative interviews as interventions that affect people with the potential to evoke thoughts and feelings, Patton (2015) highlights the power of interviewing and the need to consider its ethical dimensions. Qualitative research is personal in that the researcher enters the world of the participants who reveal what is inside them (Patton, 2015). The population to be interviewed comprised older people with disabilities. Older people and persons with disabilities are generally considered vulnerable groups and as such extra care may be required in considering ethical issues and to ensure that participants are not exploited or exposed to harm or risk (Matthews and Ross, 2010). The major ethical considerations that were considered at the outset of the study related to informed consent, protection from harm/distress and confidentiality/anonymity (Matthews and Ross, 2010). I was familiar with best practice in conducting interviews with human subjects and was guided by national documents including the National Disability Authority's *Guidelines for Including People with Disabilities in Research* (National Disability Authority, 2002) and *Ethical Guidance for Research with People with Disabilities* (National Disability Authority, 2009) and the HSE *National Consent Policy* (Health Service Executive, 2016b).

4.4.1 Informed Consent

Participants in a research study must understand what is involved in participating and why they are taking part. This entails providing potential participants with all the necessary information to allow them to give their informed and voluntary consent. This is an ethical process that includes the recognition that participants deserve due respect and consideration (Matthews and Ross, 2010). Informed and voluntary consent was a fundamental pre-requisite for participation in the study for all participants, including participants who may be classed as vulnerable. As part of the recruitment process, potential participants were given an information sheet (Appendix B). Where required, the information sheet was also provided in an accessible format (Appendix C). The information sheet outlined the purpose of the study, the format of the interview, how the data from the study would be used and issues relating to confidentiality and data storage. The information sheet also provided contact details for the researcher. This afforded the potential participants the opportunity to contact the researcher both in relation to expressing interest in taking part and to obtain further information. An information sheet was also provided to potential stakeholder participants (Appendix D).

Matthews and Ross (2010) highlight the advantage of informed consent forms as providing the participant the opportunity to be fully informed on the research as well as the implications of their participation in the study. Furthermore they may allay fears should any concerns relating to informed consent arise in the future. Consent forms, which were also drafted in accessible format and provided when necessary, were discussed fully with the participants before the interview commenced. The consent form (Appendices E & F) clearly detailed what the participant was consenting to, namely that they had received full information relating to the study, had the opportunity to ask questions of the researcher, understood that participation was voluntary and that they could withdraw at any stage or decline to answer any questions, understood how their contribution would feed into the overall study and finally that the interview would be audio recorded. I ensured that participants who had difficulty in reading the written consent form (sensory impairment) were made aware of the contents of both the information sheet and the consent form. For participants with cognitive or intellectual disabilities, I went through the information sheet and consent form fully and ensured that they completely understood the contents and had an opportunity to ask questions before giving their informed consent. As a further measure, consent was recorded on an audio recording device. In adopting all of these measures, the informed consent of all participants was obtained prior to them taking part in the study.

4.4.2 Confidentiality

In addition to informed and voluntary consent, confidentiality is a primary ethical consideration in any research study. Participants were advised both in the information sheets and the consent forms about the measures that would be taken to ensure confidentiality. They were advised that names would be anonymised and identifying markers would be generalised. They were advised as to how their information would be stored and used. I reiterated these points verbally to all participants prior to commencing the interview. However, it should be noted that in Phase Two, stakeholder participants were advised that while all efforts would be made by me to protect their identity, this could not be definitively guaranteed. I flagged to stakeholders the possibility that they might be identifiable by the information they provided. This was also referenced in the Consent Form (Appendix G). All stakeholders understood and accepted this and indeed in a number of cases they volunteered to waive their anonymity. However, when it came to writing up the findings, ultimately all stakeholders were given an alphabetised/numerical identifier, coded by reference to their expertise/jurisdiction. This was sufficient to demonstrate their relevant expertise and understanding of the research subject and their contribution to the evidential validity of the research study.

4.4.3 Research Protocol for Distressed Participants

Participants in the study were being asked to share personal aspects of their lives that may have included upsetting memories, negative experiences and painful losses. Undoubtedly some sensitive topics are more likely to cause distress (Corbin and Morse, 2003). Matthews and Ross (2010) caution that as most researchers are not trained counsellors, we may not have the skillset to deal with such reactions but that the solution lies in ensuring participants can access support should it be required. That the participants had disabilities added to the need for due regard in this area. Participants with cognitive impairment, owing to conditions such as dementia, may be more likely to experience confusion or unease in an interview situation (Heggestad *et al.*, 2013). Furthermore, given the age profile of participants, there was a strong possibility that some narratives of participants with intellectual disabilities would include a history of institutionalisation (Kåhlin *et al.*, 2015a). This possibility became a certainty for participants who had transitioned from institutional settings to homes in the community. The researcher was aware of negative connotations associated with institutionalised living, particularly in light of a number of highly publicised investigations, which had revealed abuse (RTE, 2014). Therefore, given the potential for participants to become distressed, it was essential that a robust research protocol be put in place to respond to such a scenario.

I discussed this issue with colleagues as well as supervisors who were experienced in studies of a similar nature. With reference to Appendix H, a distressed participants' protocol was devised and this formed part of the ethics application for the study. Should a participant become distressed or uncomfortable, a break was to be suggested and, if deemed necessary, a suspension of the interview and postponement to a later date. All participants were informed that they could withdraw from the interview at any stage without explanation or fear of repercussion. In the event of distress, participants were to be reminded of this option and the voluntary nature of participation.

Ultimately, the distressed participant protocol was employed in one interview. In this interview, it became apparent that the participant, who had a physical disability, also had some form of cognitive impairment, likely early-stage dementia. He became confused and frustrated, not with the interview but with his own state. From my professional background in legal practice, I had experience of interviewing people in a compassionate and sensitive manner. I was able to draw on this experience to put the participant at ease by moving the conversation to topics that made him feel more comfortable. I made the decision to end the interview early so as to avoid any potential further distress. I was also attuned to the importance of both what a participant said as well as what was left unsaid and the emotions expressed. I was able to conduct the interview in an empathetic manner and ultimately this helped to alleviate the need to employ a stronger distress protocol, such as contacting support organisations. As shown in other research concerning sensitive topics, and as evidenced here, sensitive and empathetic interview techniques can succeed in preventing the need to use distressed participant protocols (Dempsey *et al.*, 2016). Corbin and Morse (2003) opine that as researchers themselves have experienced human emotions such as anger and sadness, they should be able to connect with participants even in moments of distress. Drawing on these experiences, they can listen and be there for the participant in an empathetic and connected way until the participant feels able to proceed.

4.4.4 Ethical Approval

NUI Galway and Brothers of Charity

The Research Ethics Committee of the National University of Ireland, Galway granted formal ethical approval in November 2015. As part of the constructivist grounded theory approach (Charmaz, 2017), Phase One of the empirical study engaged with purposive sampling and, more particularly, theoretical sampling. As themes began to emerge from the data, it became apparent that the perspective of participants with intellectual disabilities and with experience of group homes in the community was missing. Accessing participants who had such experiences necessitated engagement with a service provider working in this area. Following engagement with the Brothers of Charity and adherence to their internal ethical approval application process, I secured ethical approval in November 2016. Ethical considerations and principles adhered to throughout the study have been outlined earlier in this chapter.

4.5 Data Collection

4.5.1 Interview Approach

In qualitative research, data comprises accounts of events and experiences that are inherently meaningful as they are the outcome of human interactions and intentions imbedded with meanings that inform such actions (McLeod, 2011). Bryman (2016) credits the popularity of the interview as a method in qualitative research to its flexibility. Qualitative interviewing varies between structured and semi-structured approaches on the one hand, where the researcher follows a list of topics to be covered in the interview guide, and unstructured approaches on the other, where there might only be one question, which the participant responds to and the researcher then follows up, often with the aid of prompts to cover relevant topics (Bryman, 2016). Given the exploratory nature of the research question and the desire to allow participants to present their own accounts of everyday life, in Phase One of this study, a more unstructured approach was adopted. For Phase Two, where specific insights were to be sought from stakeholders working in policy and practice, a more structured approach was required. However, notwithstanding such differences, both interview approaches had flexibility in common. Flexibility in interviewing is important so that the researcher can adapt to the circumstances of each particular interview, such as by varying the order of questions, following up leads and clarifying any inconsistencies. Furthermore, unforeseen issues may arise, such as when the participant reveals interesting information after the recorder has been turned off (Bryman, 2016). In practice, this happened in two interviews during Phase One and necessitated the taking of notes while trying not to lose the spontaneity and conversational tone of the interview.

Reflecting the unstructured approach, Phase One interviews were almost conversational in nature. Such an approach was especially appropriate for participants with a broad range of disabilities and with different experiences of community living. Adhering to a more structured approach would not have been sensitive to the need for flexibility, particularly when interviewing people with intellectual and cognitive disabilities. Furthermore, such an approach allowed participants to provide their own interpretation of what community living meant to them and to convey what they viewed as important or significant, without the researcher leading the conversation.

A pilot interview was undertaken. Pilot studies are useful in allowing the researcher to test the research questions and make necessary refinements (Bryman, 2016). From my professional work in legal practice, I had experience conducting interviews with clients and professional witnesses as well as court experience. However, conducting interviews as part of academic research is somewhat different. While some of the same skills may be utilised, academic research that seeks to capture the voice of participants requires a different approach. I was cognisant of the need to curb any natural tendencies I may have to seek clarification from an interview participant on points raised, as would be usual in legal interviews. The pilot interview was recorded and subsequently transcribed. I found this process beneficial as it allowed me to assess my interviewing technique, to discuss and reflect critically on my approach in a supervision meeting, and be cognisant of adjustments/refinements that I needed to make. As the data gleaned from the pilot interview was rich, the interview ultimately formed part of the research study by contributing to the research findings.

All Phase One interviews began with a broad and encapsulating opening question: *"Can you tell me about your life in the community?"* An interview guide (Appendix I) had been prepared with a number of prompt questions that could be used depending on the particular circumstances of each individual interview. An accessible or easy-to-read version of this was used for participants with intellectual or cognitive disabilities (Appendix J). The prompt questions were used to varying degrees depending on how the interview evolved. The prompt questions were also revised as the research study progressed. Charmaz (2015) encourages interview guides to be viewed as a means of opening the interview conversation rather than a prescribed set of questions that must be followed.

In Phase Two, stakeholder interviews followed a semi-structured format, with a number of questions focusing on the participant's perspective and that of their representative organisations on the concept of community living. Other questions related to ageing, disability and life-course policy and were broad in focus. This was deemed the best approach given that the stakeholder interviews were intended to complement the first phase interviews by drawing on certain themes. Furthermore, as the stakeholders spanned both the disability and ageing sectors and brought both a national and international perspective, questions that related to particular country-specific policies would not have been appropriate. The purpose of these interviews was to capture a broad understanding of the concept of community living from the perspective of these chosen stakeholders as well as their views on intersectionality and general policy issues. The participants were all experienced communicators and articulate in their area of expertise, well versed in the language and delivery. Therefore there was no benefit in keeping to a tightly structured interview path, as this would have lost the spontaneity and insight that a more flexible interview approach delivered. Interviews were therefore quite conversational in style and did not adhere strictly to the interview guide (Appendix K), although it was referred to in order to ensure relevant topics were addressed. Interviews were carried out via Skype/telephone or face-to-face. Given the geographical spread of participants and time constraints dictated by their schedules, the majority were conducted through Skype. All participants consented to the interview being audio-recorded.

4.5.2 Interview Experience

Interviewing for the first time in academic research is a daunting task and may present a number of challenges. Typical challenges include confronting unexpected behaviours and environmental issues, the intrusion of personal bias, maintaining focus, dealing with sensitive topics and the time-consuming and difficulty of transcription (Bryman, 2016). While many of these challenges were encountered during this research study, awareness of what lay ahead was a benefit and allowed for steps to be taken to reduce the likelihood of issues materialising and, potentially, influencing the quality of data collection and analysis.

Phase One interviews took place in a variety of settings, including day centres and participants' own homes. The setting did impact to an extent on the interview experience. Although day centres were not as intimate as the home settings, these locations were nonetheless familiar to the participant and represented venues where they felt comfortable and at ease. All such interviews were conducted in a private and comfortable room, thus removing any potential time pressures or questions around respect of personal privacy. Of the 20 interviews completed, 7 took place in the participants' own homes. Interviews conducted in participants' homes felt rather more personal, as participants invariably took the opportunity to show me their home and personal artefacts, such as photographs, that held meaning. Such experiences were recorded in the research notes taken during the interview and expanded upon in the research diary, which was completed on the same day as the interview so as to capture thoughts, and emotions that would be useful during analysis. Furthermore, interviews conducted in participants' homes extended beyond the recorded interview as there was the added dimension of social interaction through tea and chats.

A detailed research diary was kept throughout the research process, including during the phases of data collection and analysis. This diary recorded key events, such as the interview experience. This proved a highly useful research tool for reflection and also for clarification when it came to data analysis. I was able to use the research diary to remind me of the context of particular interviews as I had recorded observations. This fitted well with the constructivist grounded theory approach, adding context to the transcribed data and allowing me as the researcher to construct theory from the data, both written and observed.

4.5.3 Leaving the Field

Given my involvement with two day centres in particular, leaving the field was not as straightforward as I had anticipated. I developed a close rapport with the participants and enjoyed their company and that of the other service users, staff and volunteers. I was encouraged to return to visit the day centres and, indeed, I was invited back to visit some participants in their homes. However, ultimately I decided that it was best to withdraw from these settings for the duration of the research project. I felt this would be a cleaner break and would allow me to analyse the data free from any other distractions.

4.6 Data Analysis

4.6.1 Phase One – Constructivist Grounded Theory

Transcription

The audio-recorded interviews were transcribed fully, since verbatim transcription offers the advantage of allowing for all analytical uses (Gilbert, 2001) and was in keeping with the methodological approach adopted in the study. Owing to its iterative nature, data analysis had been an on-going process from the first interview and, accordingly, necessitated on-going transcription. Transcribing the interviews myself proved a time-consuming endeavour, in part owing to the narrative nature of the interviews. However, the transcription process did allow me to fully absorb myself in the analytical process. I could also be assured of the authenticity of the data as, following full transcription, each interview script had been rechecked against the audio recording. Approximately 120,000 words of text were generated through interviews with older people with disabilities.

NVivo

Analysis was undertaken with the aid of computer-assisted qualitative data analysis software (CAQDAS) and specifically the CAQDAS package NVivo.

Bryman (2016) acknowledges that while CAQDAS may not be for everyone, its flexibility and capabilities mean it warrants serious consideration as an analytical tool. Having become aware of the potential benefits of using CAQDAS, I completed a training course and subsequently a two-day workshop on NVivo. Using NVivo allowed me to better manage the data and make further sense of the on-going analysis that had been undertaken to that point. A key advantage of using NVivo was that it provides a method for the organisation of the coding process (Bryman, 2016).

Memo Writing

Memos were employed throughout the research study as a research tool. Effectively, memos were notes that were utilised for a variety of purposes including exploring ideas, recording research decisions and interrogating the data (Matthews and Ross, 2010). They were particularly useful for theoretical sampling and during analysis in the process of theoretical development. Memo writing represents an important aspect of constructivist grounded theory. It allows the researcher to explore the codes that have been generated from the data and to make sense of their possible meanings. Memos were made throughout the data analysis process. Bryman (2016) states that the goal of data analysis is ultimately to make sense of the data through a process of data reduction, which allows for the categorisation and interpretation. I found memos to be particularly beneficial for making sense of the data, especially in the early stages of open coding and again in category formation. I was able to use the memos as analytical tools to link concepts and see patterns in the data. Accordingly, memo writing was a way to stay engaged with the research process (Charmaz, 2006).

Coding

Coding with the assistance NVivo was carried out through a process of 'node' generation. Nodes or labels were applied to segments of data in order to categorise them. The process of coding involved initial coding with gerunds, focused coding and theoretical coding, leading to category development

(Charmaz, 2015). As analysis progressed, I applied pre-existing nodes as much as possible to the data and indeed, as theoretical saturation was approached, the need to create new nodes diminished at a corresponding rate.

Charmaz (2015) states that coding affords the opportunity to view and label data from multiple conceptual vantage points as a reflexive involvement with the data and a strategy for theory construction. Coding with gerunds or active verbs or “ing” words was useful as it kept close to the data and the participant’s own meanings. This proved beneficial as the analytical process progressed. Table 4.2, ‘CGT Coding Process’ sets out an example of the coding process, with reference to open codes relating to ‘accepting living alone’, ‘acknowledging wear and tear of life’, and ‘reflecting on unpredictability of life’.

Table 4.2: CGT Coding Process

Open Code	Focused Code	Theoretical Code	Category
Accepting living alone Acknowledging wear and tear of life Reflecting on unpredictability of life	Accepting the way life unfolded	Being pragmatic about life	Resilience

Identifying Categories

Following the coding process outlined above, categories were established. At this point a significant number of categories had been created and this necessitated further analysis in order to refine the categories. An example of this refinement process was where the category of ‘identity’ was ultimately subsumed into the final category of ‘independence’.

Theoretical Saturation

Theoretical saturation was reached when no new or relevant data emerged in a given category following the process of theoretical sampling. Therefore there was no need to continue to collect data for that particular category as its importance had been established and at this point it was well developed.

4.6.2 Phase Two - Thematic Analysis

Thematic analysis is a commonly used generic approach to data analysis that differs from approaches such as grounded theory in that it does not have an identifiable evolution nor is it marked by a distinctive set of techniques (Bryman, 2016). Braun and Clarke (2006) refer to thematic analysis as an accessible and theoretically flexible approach to analysing qualitative data whereby patterns or themes in the data are identified, analysed and reported. While promoting the flexible approach of thematic analysis, Braun and Clarke provide clear guidelines on how to carry out thematic analysis in a six-point strategy outlined in Table 4.3. Thematic analysis offered a relatively straightforward data analysis strategy that was compatible with the aim and objective of Phase Two of the study.

Table 4.3: Interpretation of Braun and Clarke Six-Point Strategy

Phase	**Process**
Familiarisation	Transcribing data, reading and rereading data, noting down initial ideas.
Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Reviewing themes	Review and refine themes – this may necessitate deletion of themes that are not really themes and further breakdown of other themes.
Defining & naming themes	Identify what each theme is about and write analysis of each theme.
Producing a report	Having a fully worked out set of themes, final analysis leads to writing up of a report.

Analytical Process and Procedure

As with the Phase One interviews, Phase Two interviews were transcribed verbatim by me for the aforementioned reasons. This afforded me an in-depth familiarity with the data from an early stage in the analytical process. Analysis was again undertaken with the assistance of NVivo. The steps set out in Table 4.2 were followed and gave rise to the identification of themes, which were written up in the findings Chapter 6. In following the six-stage process, I generated initial codes from the transcribed interviews and then searched for themes by grouping these codes into emerging categories. I then reviewed the themes in order to make better sense of the data and to ensure that I was accurately reflecting what I was discovering from my participants. I then defined and named the themes, with three themes with sub-themes ultimately emerging from the data. This process necessitated a close connection with the data and ensured that the themes were deeply rooted in the data, thereby accurately reflecting the participants' viewpoints on the study topic.

4.6.3 Writing up findings

Phase One findings were written up on the basis of the five categories that emerged from the data: resilience, independence, social interaction, support, and home and environment. In writing up the findings under each category, there is a risk that one loses sight of the individuals whose experiences are at the heart of the study. For this reason, it was decided to use one particular participant as a case illustration for each category. This vertical form of analysis allowed the richness of the data to be more clearly demonstrated. It also personalised the participant, giving life to the narrative through the provision of context. Following the case illustration for each category, horizontal analysis across the data was undertaken. Phase One findings are detailed in Chapter 5. A more comprehensive vignette of each of the case illustrations may be found in Appendix L.

Phase Two findings, which are presented in Chapter 6, revolved around the three themes that emerged from the data. These themes were Silos Rationalised, Community Means Community, and Ageing and Disability as Processes with associated sub-themes.

4.7 Study Rigour

This study was carried out with mindfulness about the need to adhere to best practice in qualitative research and to ensure that credibility could be claimed and assured. Study rigour was therefore a primary objective throughout the study, from ethical approval through to data collection and analysis. Denscombe (1998) notes that methods and conclusions must be justifiable and that this justification should not merely be an assertion or an act of faith, but rather must be demonstrated to be based on reasonable decisions taken throughout the research process. Mindful of this, I considered each of my decisions in light of the overall aims and objectives of the research and sought to ensure that they would withstand scrutiny on the basis of being reasonable and justifiable decisions.

4.8 Researcher Reflexivity

In discussing the concept of reflexivity, Bryman (2001) alludes to the sense of the researcher having an awareness of their role in the research process and the ultimate construction of knowledge in the social world they have chosen to explore. This means reflecting on the methods, processes and decisions that have been made in this process. In commencing this study, I had an idea about what I hoped to achieve and this influenced my chosen methodology and dictated the methods that would best help me achieve my research aims. However, as I became more engaged in the research process, I encountered both theoretical and practical issues that challenged my preconceptions about what it means to “do research”.

Theoretically, the research process and the emergent findings challenged my pre-existing views on the research topic and forced me to think more analytically. Practical challenges relating to accessing participants and conducing fieldwork were also important steps on my ‘apprenticeship' as a researcher. Responding to these challenges made me refine what it was I hoped to achieve and think more deeply about the research process. I came to better appreciate the role of participants in research as co-constructors of knowledge and my role as a researcher in communicating this knowledge.

4.9 Chapter Summary

This chapter has provided an account of the methodology including the research paradigm and researcher positionality as well as the methodological approach and methods employed in the empirical component of this study. The considerations that influenced the chosen methodological approach for the two phases of the study have been discussed. Moving on from this, sampling and participants have been discussed as well as ethical considerations and the ethical procedures adhered to throughout the study. Data collection and data analysis for both phases have been discussed. Finally study rigour and research reflexivity were dealt with as important components of the research process. Overall, this chapter has sought to clarify the steps taken in conducting the empirical component of the study and the decisions that were taken through this process. They ultimately gave rise to the findings that are presented in the next two chapters. The findings from Phase One, being the community interviews with older people with disabilities, are set out in Chapter 5. Findings from the stakeholder interviews are presented in Chapter Six. This follows the order of data collection and analysis and, furthermore, reflects the aims of both phases being voice and insight respectively.

Chapter Five

Findings Phase One – Community Interviews

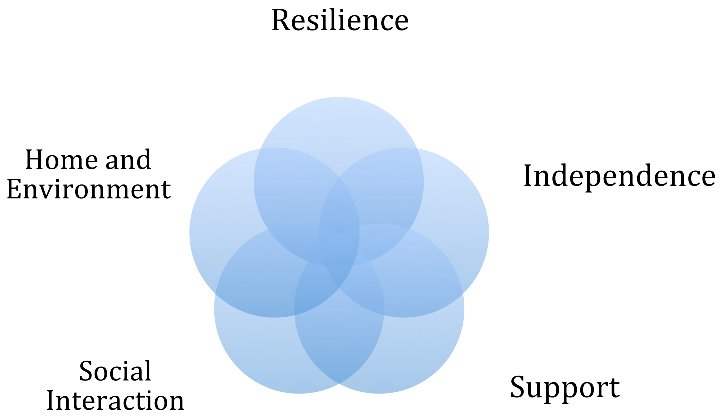
"I'll keep going until the wheel falls off"

5.1 Introduction

This chapter presents the findings of the empirical study of community interviews carried out with older people with disabilities. The central research question concerned how community living is conceptualised and experienced for this group. Drawing on the methods of Charmaz (2015) and the reflexive and iterative process of coding, a number of themes were identified. Through the coding process, nodes or labels were generated and applied to segments of data in order to categorise, and ultimately make sense of the data. This process involving initial coding, focused coding and finally theoretical coding, giving rise to category development is expanded upon in Appendix M.

Community living, as conceptualised for older persons with disabilities through their subjective lived experience revealed resilience, independence, support, home and environment and social interaction as essential components of meaningful community living. The five themes, depicted in Figure 5.1 'Domains of Community Living' are interlinked, with resilience serving as a connecting thread and the prism through which the other components may be viewed and better understood. In the following sections, a case illustration has been employed for each theme in order to elucidate concepts before moving on to present data from across all study participants that deepen our understanding of the components that reflect experiences of community living for older people with disabilities.

Figure 5.1: Domains of Community Living



5.2 Resilience

Resilience resonated throughout the interviews as a significant factor in community living for older people with disabilities. Resilience was interpreted in the context of serving to fortify participants in maintaining lives in the community given changing circumstances and new realities, often experienced in the wake of physical, emotional and psychological adversity. Events and experiences over participants' life courses served to foster and augment their resilience. For older people with disabilities seeking to live in the community, there is oftentimes a negotiation between what they may want or need on the one hand, and what they are prepared to accept on the other. This negotiation colours all other aspects of community living and demands a degree of both resilience and pragmatism. In this way resilience was understood as a process as opposed to an inherent personality trait (MacLeod *et al.*, 2016, Hardy *et al.*, 2004). This is a process involving negotiation, adaptation and management of significant stresses and life events, with capacity impacted by resources, life and environmental factors (Windle, 2011). Research (Terrill *et al.*, 2016) also suggests that resilience in older age owes more to experiences over the life course that the length of time with a disability. This was evident throughout the narratives of older persons with disabilities in this study.

5.2.1 Case Illustration: Matt

Gender	Male
Age	Mid 80s
Disability	Physical (mobility impairment)
Marital Status	Widowed
Children	6
Living Arrangement	Lives alone in own home
Location	Rural, countryside
Professional Status	Retired manual worker

Matt, in his mid 80s and living alone, epitomised the theme of resilience. Matt had a significant mobility impairment, which led him to experience disability. Having been widowed over 30 years at the time of interview, he had raised six children, the youngest being twelve at the time of his wife's death. He was deeply affected by the sudden and traumatic loss of his wife, Trish, and referenced her in terms of his happiness throughout the interview: *"If I only had herself in it, I'd be happy."* The love that Matt felt for Trish was woven into the fabric of his life story. He had found his life partner and his own happiness had been grounded in ensuring her happiness. Matt had striven to build the home that Trish had wanted and had demonstrated tenacity in so doing: *"Well I was living in the town and my wife always wanted to go out the country, have mercy on her. I was looking for a site but hadn't much money. I kept going forever until I got a site and then I started building it."*

Trish's death had an undeniably profound effect on Matt and the ripples of loss resonated throughout his narrative. Trish's untimely death after a short and misdiagnosed illness left Matt to continue the task that they had begun together of keeping a home and raising their family. Indeed, he admitted to having fallen to pieces when she died: *"I lost it then after her I did."* Although his children and grandchildren were a source of comfort and joy, it was evident that they could not fully fill the void in his life that had formed upon the death of his wife, which in his own words *“broke my heart anyway.”* Despite this loss and the ensuing demands of keeping the family together, Matt carried on. From his perspective, he felt that he no other choice but to pick himself up and do the best he could. This evidences the resilience that Matt drew upon and which allowed him to persevere and see his children educated and moving on into their own lives. Surviving in the wake of loss was not easy and Matt reflected on the personal toll these experiences had taken: *“It was a hard life, you don’t know it…I survived anyway, I did.”*

In attempting to understand the resilience that Matt demonstrated as an older man experiencing disability, Matt’s earlier life-course experiences offered some insight. He came from a large family in rural Ireland and was called upon to work on the family farm for extended periods during his formative years. This necessitated prolonged absences from school, which had a profound effect both at the time and into later life. He suffered corporal punishment at the hands of his teachers as a consequence of his frequent absences. His story is indicative of a time and place in Irish history when authority often went unquestioned and unchecked. Despite the passing of time, Matt still harboured negative sentiment towards his parents for his poor education and the difficult experiences he had in school. He also experienced consequential difficulties in negotiating his adult working life hindered by poor literacy: *“I’m not ashamed of it. Maybe my parents should be ashamed of it but that’s no good now, they’re gone and goodbye to them.”* Matt’s lack of formal education was a source of shame and stress to him when he began his working life. However, with an ingenuity that belied his claim to be unintelligent, and with the support of his wife, he managed to find ways to overcome his educational shortcomings. However, again reflecting on the difficult nature of his life illustrated that this was not an easy feat: *“Oh I got through life the hard way.”*

Having not benefited from a good education himself and having also experienced the difficulties in his working life that emanated from this, Matt was determined to ensure that his children received a good education. That this was a priority shared by his late wife perhaps explains Matt's determination to see the children well educated in the aftermath of her death. He was pragmatic in that he accepted the hand that life had dealt him and drew upon his inner determination to ensure that his children would not be any further disadvantaged. While Matt could not compensate for the loss of their mother, being a good provider and ensuring that their material needs were met was within his control. He was also determined to see them avoid any pitfalls in their formative years and succeed in life:

> *"I was trying to keep them all together…It was hard like do you know. There was an odd boy going off with girls you know. I had to be very cagey with them because they could get them into trouble young you know…There was girls going with fellas that I didn't like you know. They were better than myself you know, not saying they weren't, they could be but they had nothing do you know, they could get them into trouble. Lots of things like that you know."*

Matt found himself in the unenviable position of fulfilling a dual parenting role and having to make decisions without the benefit of consultation and support: *"I had no one to back me, no one in this wide world to back me, no one. Whatever I done or didn't do."* Nonetheless, despite the difficulties encountered raising his family alone, he succeeded, in his own view, in creating a happy and unified family unit that was a considerable source of contentment in his later life. Most of his adult children were married with their own children and lived in the wider county. That they had gone on to lead what Matt believed to be successful lives was a source of tremendous pride for him. It was evident that Matt equated work with success and this was reinforced by his own life experience *"I do like to see them all going well. I do love to see them working I do. I love to see them going well."* He still worried about his children, especially those who remained unmarried. It was clear that his measure of a good life was also intrinsically linked to marriage, children and home. He worried about relationships that had not worked out, the children that had not come along as well as other difficulties experienced by his children. However, he was pragmatic about life and his attitude was one of acceptance with regard to what would come to pass. Having done his best and played his part in their success was a source of pride and further fortified him in dealing with his own challenges. Furthermore, his grandchildren offered much comfort and joy. It was apparent that Matt felt he had a natural and easy relationship with his family that was grounded in a deep and mutual love and respect. They enjoyed and looked forward to their times together: *"They love Christmas to come until I'll join them."*

Matt was at times troubled by negative thoughts that came at night when he had no confidant to share his burdens. These periods were arguably borne of loneliness and an inner sadness that could be traced back to the ever-painful loss of his wife. This loss had a deep and lasting psychological effect on him. However, he drew on inner strength and overcame such dark episodes: *"Everything came into my mind last night. I broke down. And I had no one in the house to have a chat with or anything. I broke down last night I did. I got over it. I'm here now."* Throughout his life he had to overcome hardships and knocks and yet he had not let these experiences embitter him or impact on his ability to find joy in life. In facing trials and triumphing over adversity, he had built a store of inner strength that he continued to draw upon. He was resilient in both outlook and attitude. Although pragmatic about his age and mortality, he continued to find enjoyment. He overcame the negative thoughts that permeated his consciousness and instead looked to the future, expressing hope for further happy family events: *"I'd like to see babóg running around before I go my own way."*

Matt interacted socially in the wider community by attending a community day centre and engaged in generationally and culturally rooted pastimes, such as going to funerals. He continued to meet with childhood friends to talk about old times. This allowed him to be philosophical about the nature of work and life. He was reflective about life experiences and was able to look back on those times through the prism of age and experience and this afforded significant self-awareness, personal and institutional: *"Well do you see, what I done to myself, I killed myself and here I am now not able to walk…if I went back now I'd never do it, I wouldn't. No way, no way, no way but sure a lot do the same as I done."*

Resilience, to varying degrees, featured in all the participants' narratives. It manifested most notably in responses to challenging life events and changing personal circumstances. For participants such as Matt, it was immediately identifiable as the stand out characteristic that coloured all stages of the life course. However, for others resilience was more subtle and nuanced. Resilience was identified primarily though the subthemes of 'going it alone' and 'responding to new realities'.

5.2.2 Going it Alone

One of the most challenging life events is bereavement and loss of family or friends was an experience shared by a number of participants. Among such loss, the death of a spouse resonated as the most profound. For older persons navigating the complexities of life with the added dimension of disability, the absence of this uniquely personal relationship can be particularly difficult. One participant experienced this loss in midlife and the ripples were still apparent over two decades later: *"I was married, my wife died just over 20 years ago and yeah, I found that was maybe the worst thing that can happen in your life" (Mark, mid 70s, physical disability)*. This is illustrative of the profound impact of loss. For Mark, the experience of disability in older age was particularly challenging in the absence of spousal support or indeed that of any close family. However, Mark also demonstrated significant resilience in facing his current situation. He was determined to maintain his life in the community as best he could by continuing to advocate for himself and the supports he needed as well as making an effort to engage positively with others: *"We are all climbing the mountain and there are pitfalls and there are things catching you and we should be reaching out helping hands as we go up."*

Eithne had experienced the loss of her spouse in a manner apart from the physical sense. He had advanced dementia and this had profoundly changed the nature of their interactions. By Eithne's own admission, their symbiotic relationship was born of mutual need. Nonetheless, there had also been companionship and friendship. Losing this aspect of the relationship was deeply felt by Eithne as she had lost a confidant: *"This has opened me up, being able to talk to you, because I can't talk to my partner at all. He doesn't talk at all. If he talks at all it's to shout if something is wrong or something. Its very difficult"* (Eithne, early 90s, physical disability). Despite the lack of close family in their proximity and the worry about what the future would bring for both of them, Eithne was determined to keep going herself and, out of a sense of duty, to take care of her partner. She had come to terms with her partner's condition and learned how to manage him:

> *"As much as I have no love and he has no love but here is a commitment I think…I do worry about him but there is nobody giving me answers, nobody. He's got dementia, that's all they say but he is 6 years. It's an awful long time, an awful long time but I can live with him now. I have to live with him."*

Going it alone after experiencing loss necessitates acceptance of the realities of that loss and the way life has unfolded. It requires strength and determination and can be particularly challenging in the absence of other family support, as illustrated by Mark and Eithne's circumstances. For these participants, resilience manifested itself in their ability to fill the void of loss by engaging with the wider community and in so doing they mitigated somewhat the effects of loss:

> *"I was involved in a local sport club and I got involved in a local charity, the Saint Vincent de Paul. I was in that a number of years. I found it was necessary to get involved in things when you get a kind of void so to speak in your life. I felt it was important to get involved in things"* (Mark, mid 70s, physical disability).

Some participants also presented getting on with life in the aftermath of loss as a conscious choice they had made. For Joe, the experience of living alone after his wife died represented unchartered territory. Presented with the option of attending a community day centre, Joe took this opportunity rather than spending his remaining years *"looking out the kitchen window".* Rather than internalising the loss of companionship that his wife and work afforded him, he decided to put himself back out in the community and get on with things as best he could: *"I found it awful hard to pass the time. Like, as I told you the wife was dead and I was living alone and if you worked the hours I worked, you don't switch off overnight. Very, very difficult living on your own"* (Joe, early 80s, physical/sensory disability).

5.2.3 Responding to New Realities

Aside from bereavement, participants' narratives revealed other significant life transitions, most notably moving to community from institutional residence, adjusting to life post-retirement, and managing disability. These were significant transitions in participants' lives, and in adapting to new realities they demonstrated resilience. For participants with intellectual disabilities, resilience was uniquely manifested in their transition from institutional residence to community living. These particular participants all had a history of institutionalised living and it was only in middle or later life that they had been afforded the opportunity to live independently in the community. Some participants reflected on the constrained nature of life in an institutional setting devoid of independence and choice: *"Write down everything. What time you go to bed, what time you get up, you can make no cup of tea at 9 o'clock, no" (*David, mid 60s, intellectual/physical disability). The regulated framework of order and structure that epitomised residential living had become normal. The move to community was a move into the unknown and represented a major life transition. Creating an independent life in the community for the first time demands much determination. It necessitates breaking with the institutionalised structures and embracing independence, which can have its own challenges. That these participants could make this move and continue to adapt to life in the community highlights their resilience: *"On my own. We get up and we do how we want to do"* (David, mid 60s, intellectual/physical disability).

Older age in itself brings change and, for some participants, one of the biggest changes was retirement: *"And they put me out to grass and I came 65. That was the thing to do, get rid of me"* (Joe, early 80s, physical/sensory disability). This was particularly apparent for participants who had dedicated a significant portion of their life to their work and for whom marriage and children had not featured. Adjusting to the new reality of retirement was challenging: *"I found a big change when I retired. I missed work terribly and I found it hard to create a routine for myself"* (Brigit, mid 80s, physical/sensory disability). Such participants recognised a negative void formed in the absence of routine:

> *"The other thing is that for a period of time after I retired, even though I have a great interest in computers and I read a reasonable share, I did spend a bit too much time at home at the house on my own and it was not doing me any good you know. There is no doubt about it, I was suffering from that"* (Dermot, early 80s, physical/psychosocial disability).

However, participants dealt with their new reality by putting themselves back out into the community. They made a conscious effort to interact with others and such engagement was sometimes difficult given the added dimension of disability. Cognisant of the need to adapt to life post-retirement and form new routines, participants such as Dermot, made a conscious choice to step outside their comfort zone and interact socially outside the home: *"Even yet I'd still go for lunch to {former workplace} three or maybe four days in the week. That does a lot of good for me because I meet people that I used to work with and see the various changes in society and attitude"* (Dermot, early 80s, physical/psychosocial disability).

Resilience was also demonstrated in the manner with which participants managed their conditions and attempted to alleviate the consequential disability they experienced. For one participant, this meant viewing his various conditions independently rather than collectively. In this sense, he could better cope with their impact and avoid feeling overwhelmed. Adopting this outlook and showing resilience in the face of persistent setbacks worked for this participant as an adaptive strategy as he could compartmentalise his conditions into manageable blocks: *"There is a particular medication that I use, it gets me over it when I feel it coming on, and I have a chat with my GP. We sit down and have a chat and it has worked. At this stage I know that I will get through it so that is basically it"* (Dermot, early 80s, physical/psychosocial disability). Managing new conditions and coming to terms with the changes that such conditions brought about was challenging. As Eithne's physical impairment became progressively worse, hospitalisations also became a more frequent occurrence. However, she was determined to pick herself up after each setback: *"Please don't let me fall but then I fall and bang and back down again in the hospital. And I get right down and I come out again and build myself up again"* (Eithne, early 90s, physical disability).

Facing new realities and accepting that things may never be quite as they were involves a degree of pragmatism. Sadie was pragmatic in outlook regarding the future and the likely downhill trajectory of her condition: *"I probably haven't reached that stage but it's a debilitating disease, it progresses…and I'm here and I have to look at life like that, I'm here"* (Sadie, mid 70s, physical disability). Others like Brigit, took steps to manage their conditions even though it was not what they might have wanted: *"I am more confident when I have the stick and I do find that people will leave you a way when they see someone coming with a crutch or a stick. I don't like it but you have to learn to accept it if you need it"* (Brigit, early 80s, physical/sensory disability).

Overall, participants were pragmatic as regards their impairment and disability. Sadie felt that you had to work with the cards you had been dealt: *"you know you kind of balance out and you do the best that you can and you get on with your life"*

(Sadie, mid 70s, physical disability). Joe succinctly enunciated this resilient spirit in his determination to continue to make the best of life and *"keep going until the wheel comes off"* (Joe, early 80s, physical/sensory disability).

5.2.4 Resilience Summary

Resilience, in the sense of dealing with challenges and adapting to new realities, featured significantly in the findings. This is perhaps unsurprising when considering the life-course dimension of both older age and disability. Personal, institutional and societal factors impact on the lived experience of community living. As circumstances change, so too do these factors and responses are linked to resilience. However, resilience developed over the life course by virtue of experience, can also be fostered. This is significant when considering how older persons with disabilities may be better supported to live well in the community. The following section will address the theme of independence, which was closely linked with resilience in experiences of community living.

5.3 Independence

Independence emerged as a second key theme from interviews with older people with disabilities. This is also not surprising given that community living encompasses both the elements of living independently and being a part of the community. However, this is not to underestimate the interdependent nature of life, as independence is maintained and enhanced by factors including our supportive relationships with others. In the physical sense, independence manifested in the participants' capacity to live independently in their own homes and their ability to undertake tasks for themselves and interact in the community. Independence was also present in decision-making autonomy, whereby participants were free to make choices for themselves. Finally, independence was identifiable in the attitude and outlook of the participants. Independence is intrinsically linked to the other themes and this highlights the interconnecting nature of the components of community living and its multifaceted conceptualisation in the lives of older persons with disabilities.

5.3.1 Case Illustration: Frank

Gender	Male
Age	Early 50s
Disability	Intellectual disability
Marital Status	Single
Children	None
Living Arrangement	Shared group home in community setting
Location	Urban town, residential estate
Professional Status	Part time supported employment

Frank's narrative epitomises the independence that emerged from the broader empirical study. Frank had an intellectual disability and lived in a small town community in a group home with other service users. He obtained support from a service provider in the locality. Although Frank did have family, family members did not live in the locality and did not form part of his day-to-day life.

Frank's journey to community living had many parallels with the experiences of other participants with intellectual disabilities. He had a history of institutionalised living, having spent a significant portion of his life in a residential setting. This is significant in the context of the life course, as experiencing limitations in independence and autonomy gave Frank a particular appreciation of the freedom he experienced in the community in his later years. He succinctly conveyed what community living meant to him: *"well it's freedom"*. The move to community had been positive for Frank: *"I was glad to get out into it. I'm living with the other lads up there. They are pulling out all right and I am pulling life with them. You know other things that you couldn't do you can do better in it."*

Community living for Frank meant having the opportunity to do things that were previously closed to him. In having these opportunities, he felt he could get on well in life. It is a good measure of meaningful community living at any age when one can *“know it’s on you’re going instead of being back”*. Frank was afforded the opportunity to form connections that would have been harder to create in his previous institutionalised living arrangement. Having a stake in the community made for a more meaningful life and the analogy he used was that of being invested in society: *“It’s keeping people happy isn’t it? Which, as I was saying like, they say it’s a long winter but it’s invested. It’s invested in society, in the community.”*

Frank’s analogy of it being a long winter was reiterated in his narrative and spoke to the passing of time and again that sense of having purpose:

> *“Well in terms of life, in terms of life, in wintertime you always see when it is when you are in the community. There is more to it I think. It is like when it’s not you find it an awful lot more…You can do what you can do now in the wintertime when you are out in the community but being back, back in the bungalow and going out to the workshop it’s boring. Getting you down, it’s getting you down. There is no opportunity in that so there isn’t. No there is not.”*

Having opportunity to engage in community activities was evidently an important aspect of community living for Frank. Frank’s connection to the community was fostered though having a job and interacting socially in community life. In turn, this was made possible by virtue of the independence and autonomy that living in the community facilitated. Having a job was significant for Frank as he felt it was *“nice to have a job”* and he enjoyed the nature of his work and his interactions with colleagues and customers. Frank’s employment in the town made him feel a productive member of the community and was an example of the investment that he spoke of.

For Frank, living in the community also meant being able to choose what to do with his time, what hobbies to pursue and the manner of socialising with friends. He contrasted this with institutionalised living. In the community, he felt he was *"doing an awful lot more than what we were doing"*. This freedom was clearly an important dimension of the independence that Frank enjoyed: *"It is and things can go on better. It's more variety, more than where you were because there is a thing getting to it like and it's gone out of it now when you are out in the community. And you can do absolutely anything you like."*

Frank enjoyed his leisure time away from work: *"I have the weekend to myself"*. Coming and going as he pleased meant even something as simple as choosing when to go to mass was significant, given his past experience of institutionalised living formulated on routine. While Frank still appreciated routine, it was now on his terms and open to change: *"I go to mass every Saturday evening if I can. If not, I'll go on Sunday."*

Frank also connected independence with respect and the positive feelings this evoked for him. Respect was couched in terms of making decisions and being held accountable for those decisions. Having the decision-making autonomy to make choices that are respected also means dealing with the consequences of those choices. Frank felt that this was an important aspect of living in the community for both him and others: *"Well they can get on in life better. You are respected and sometimes you are on your own passing through and can't be reneging like that."*

Independence, as conceptualised by Frank, was also intrinsically linked to having a home in the community. Having a home in the community was a further anchor that represented his investment in the community. He had established a routine of shopping and socialising that connected him to the locality. On a more fundamental level, even having his own room was a significant marker of independence for Frank, as he remarked that he could *"do what I want with it"*. Frank was happy in the community, living the independent life that he had always wanted. He was content with his life and could not wish for things to be better, remarking, *"I think things is sincerely well."*

While Frank had family, it appeared from his narrative that family members were not particularly close, with the exception of his mother, for whom he demonstrated affection and concern. Frank dictated the level of interaction with the rest of his family: *"Well I'd see them as often enough as I please."* However, by contrast, having friends in the community was incredibly important to Frank. He had friendships with his housemates and also with the people from whom he received the support. While appreciative of the help they provided, he also highlighted that the capabilities of people are sometimes overlooked: *"Some do a lot more than what you would think they would. They're doing fine they are."* It was evident that he believed life in the community was something that could be enjoyed by more people, if only they could be given the opportunity to build on those capabilities:

> *"Some of them beside you are farther than I was in {institution name} anyway. There is going out more and travelling going on than in the bungalow. When that went away I was glad it had. I'm not going back to the bungalow, going in the one place all the time. Places that are avoided now an awful lot since we moved out in the community."*

This statement again highlights Frank's positive feelings about the move. He was content and the independence it gave him also fortified his resilience and gave him the confidence to live the life of his choosing in the community: *"You are satisfied. I don't think there is anything that you cannot survive."* This speaks to Frank's ability to be independent, something that is often underestimated. The independence of Frank, as a person with a disability who was also coming to experience older age, was enhanced though living in the community. His sense of self also flourished to the point that he was confident of his own strength and capabilities: *"There's more variety outside so there is. You can manage much more clearer too so you can. Self defence like its an awful lot and side effects. The* *advantage is much more, much more, much more than you thought."* For Frank, this was central to what it meant to life a meaningful life in the community: *"There is stuff happening now that wasn't happening like. Because being sufficient like, its behind like, it's behind life, where I was an awful lot. Where it is now, in the community, you are more satisfied. You can avoid it an awful lot more."*

For Frank, allowing independence to flourish had wide-reaching benefit: *"It's so happy and harmless like to the people who got that far…you can stay out and get on well."* Moving forward in life and having opportunities was important to Frank as he felt it was part of the *"naturalness of life that you would"* have such opportunity. Frank's narrative portrayed the importance of independence in its various guises. Indeed independence was revealed by all the participants to be a factor in their lived experience of community living. They identified as independent, experienced independence and strove to maintain their independence in the community.

5.3.2 Identifying as Independent

Although independence was important to all participants, for some it was an integral part of their identity: *"Living independently I suppose, I've lived independently all my life, practically all my life. I know no man is an island unto himself"* (Mark, mid 70s, physical disability). Mark's remarks are indicative of an independent identity that at the same time recognised the interdependent nature of life. Identifying as independent was present in many of the narratives: *"I'm independent now in {town}, the best thing in the whole world"* (Shane, early 50s, intellectual disability). Participants asserted this aspect of their identity in a number of ways, including in their refusal to give up the activities they enjoyed before they came to experience disability: *"I went on the train to Dublin there. I try to maintain my independence as much as I can and I used to go to Dublin quite often"* (Joanna, late 70s, physical disability). This refusal was present despite the disabilities they came to experience as a result of their conditions and impairments: *"I still do the boules. I know where to stand and where to throw it"*

(Ronan, early 80s, sensory/cognitive disability). This assertion of independence also manifested in a reluctance to give up any degree of independence because of the limitations of their condition: *"The first time in and I said I am never going to be in another wheelchair. I'm going to dodge it somehow someway"* (Joanna, late 70s, physical disability).

Some participants viewed giving up aspects of independence as a capitulation to their condition and they were determined to try to avoid this outcome: *"I do my own thing, you know I just day to day, I do everything I can. I don't want to give in to the blindness at all if I can help it"* (Catherine, late 70s, sensory disability). Indeed, for some participants independence was so woven into their identity that being anything less than independent, despite their condition, was not something they really considered: *"And I suppose I don't even consider Emily, I don't reflect enough on how I could become less than independent"* (Michelle, late 50s, physical disability).

Participants were proud to identify as independent, often signifying continuity of experience over the life course: *"First of all, I always was an independent type of person, I was used to doing things on my own and so on. I never minded going anywhere on my own"* (Dermot, early 80s, physical/psychosocial disability). Furthermore, they acknowledged the role that this aspect of their identity played in their ability to experience meaningful community living. The ability to self-advocate was identified as an important aspect of living independently: *"I mean certainly where I am concerned anyway, I do feel, perhaps I'm too, how would you say, cosy in my corner because I know how to look for something if I needed it"* (Brigit, early 80s, physical/sensory disability). Brigit also asserted her independence through her refusal to move closer to family after retirement and after she began to experience a series of health setbacks. Instead, Brigit moved house in order to make living in the community more accessible: *"One of the reasons I thought when I retire I want to move somewhere. And they thought at home I'd go back home to {home county} you know. But no, enough of them down there."* For John, still being able to do household tasks was an important signifier of his independent identity: *"Only yesterday there were remarks that I was spotted with the hedge clippers"* (John, early 80s, physical/sensory disability).

Catherine highlighted that wanting to be independent despite differing limitations was a desire shared by many older people in the community: *"I like to be independent and there's lots of the old people around here now and they are in the same boat but in a different way"* (Catherine, late 70s, sensory disability). This was evident for Joe, who despite increasing limitations in activities of daily living, still identified as an independent person: *"Some mornings I'm able to get up myself. Before all this happened I used to go to mass every morning, like you know I was never someone to lay on in bed in the morning. I got up this morning now at 10 past 5"* (Joe, early 80s, physical/sensory disability).

For participants with intellectual disabilities who had made the transition from institutionalised living to community living, identifying as independent was essential. Indeed, it was perhaps the most central component of community living, as being independent opened the door for many other aspects of life that are closed to people who live in institutionalised settings: *"We need to move away from all that institutionalised way…they are still there, still happening, because all those situations are downright ludicrous in this day and age honestly"* (Fiona, mid 50s, intellectual disability).

5.3.3 Experiencing Independence

The actual experience of independence was extremely important to participants. For some, it was the best part of living in the community: *"I love it. I'm here eight years, about that. And I cook my own dinner and I do my own shopping across the road and I pay for my own bills"* (Liam, mid 60s, intellectual disability). For Liam, making decisions and doing things for himself was an integral part of what it meant to live in the community: *"I had to get new blinds. The blinds were all broken. Hopeless. I had to pay them out of my own money"*. The fact that he managed his own finances and household bills was a source of pride for Liam:

"Oh I'll pay that myself…the girl has to do it for the rest of the peoples, they can't do it. I go to the post office. I wait 'til Friday and I do that." Positive feelings were derived from self-sufficiency: *"I do the cooking myself now…I feel good about it"* (Shane, early 50s, intellectual disability). This was significant as even this degree of independence had been absent in Shane's previous institutional residence. For Shane, living in the community meant that people *"make their own choices now."*

Being heard and having decisions respected was also important: *"It is very important for some people…to speak their point and have to voice their opinions and also that they should be respected as well and given support."* (Fiona, mid 50s, intellectual disability) The link between independence and self-advocacy was made: *"You need to be more vocal about things"* (Brigit, early 80s, physical/sensory disability). Conversely, participants highlighted experiences in their life course when they lacked independence: *"I go to town by myself, you come home, coming home, put on my meal. You are working with me…you come home by half 10, me come home by half 5. They write in the book. Then staff coming in and saying you are late coming home"* (David, mid 60s, intellectual/physical disability).

Seamus contrasted this experience with his life today: *"I go out by myself. Go into town, go everywhere."* Experiencing independence gave Seamus more opportunities: *"Get out and meeting friends. Meet more friends and meet everybody outside."* Liam echoed this sentiment as independence for him meant doing what he liked with his free time: *"Oh it's lovely, I can do what I want. Sunday, I go for a drink"* (Liam, mid 60s, intellectual disability).

The need to maintain independence, even when negotiating supports, was emphasised. Mark asserted his independence by challenging the level of support that he had been given lest he be classed as dependent. He wanted to have a say in his care arrangements and thereby retain control in the process:

> *"I think it was basically the hospital found that I would need it after the medical intervention, if you like, on my spine. Maybe I'm very stubborn myself,*

> *I said I'm not an invalid. I would be put into that category if I accept this help. So eventually they said well it's just a temporary thing. They wanted to come 7 days a week. So I said well I am doing something on maybe Saturday and I like to do something on Sunday. So eventually I got it down to 5 days a week"* (Mark, mid 70s, physical disability).

This element of voice and being listened to is central to independence and community living for older persons with disabilities and was acknowledged as such: *"Yes, let the voice be heard. But really people want to be talked to and want to be respected. Like the dignity of the person is something that can be lost when a person is older or when a person has disabilities"* (Michelle, late 50s, physical disability).

5.3.4 Maintaining Independence

Maintaining independence emerged as an important aspect of community living, not least as a means of avoiding unwanted institutional care. Although a minority of participants thought that residential care could have some merit in exceptional cases, such as advanced dementia, it was not an option readily entertained. In one participant's view: *"For me a nursing home is a last resort"* (Michelle, late 50s, physical disability). Overwhelmingly, participants demonstrated a strong desire to remain in their own homes: *"Everyone likes to stay in their own home. For as long as I can"* (Sadie, mid 70s, physical disability). John echoed this sentiment, remarking: *"I'm going to stick it as long as I can"* (John, early 80s, physical/sensory disability).

In order to maintain their independence and hopefully avoid, or at the least postpone, entry into residential care, participants were willing to compromise. This included acceptance of help from family and friends or within the context of more formal support provision. Some participants were already receiving this support, while others were open to accepting it in the future: *"Oh I would of course yes, very definitely"* (Dermot, early 80s, physical/psychosocial disability).

However, this was firmly in the context of helping them to remain in their own homes and avoid residential care: *"Right here and get whatever care I can get. I do not want a nursing home"* (Brigit, early 80s, physical/sensory disability). Indeed, for this particular participant, while prepared to accept some assistive equipment in the home and even to entertain the idea of future home help, the present was a different matter: *"I could get help but I don't require it you know. If and when, I know I can have it. It was offered to me"* (Brigit, early 80s, physical/sensory disability).

Participants also showed ingenuity in adapting their homes to increase their conduciveness to independent living. This determination was indicative of attitudinal independence. For one participant, the solution was to make her home more accessible and therefore age/disability friendly:

> *"I always found it hard over the bath but it really got terrible so I was one of those people who applied on my own for a grant for the putting in of a shower…and they are good in the county council in that they ensure that these are walk in showers with handgrips and all that kind of thing"* (Michelle, late 50s, physical disability).

As in Michelle's case, participants demonstrated their independence in their determination to do things in their own, in their own time and on their own terms: *"I'm thinking of getting myself there those steps out of there and have a slope up. But I will do it of my own accord"* (Brigit, early 80s, physical/sensory disability). Participants were aware of their needs and what they required to maintain independence. This included an awareness of limitations of the home and what would be required in order to improve their situation: *"I'm on a transfer list at the moment because my health problems are making it more difficult to negotiate the stairs"* (Mark, mid 70s, physical disability).

Participants expressed frustration at a perceived lack of formal supports. This extended to not obtaining the therapeutic and medical interventions that would help them maintain their physical independence and by extension their ability to remain living in their own homes in the community:

> *"I feel that it is put on the back burner type of thing because my condition is deteriorating and there might be a time when I can't do physio at all. I don't want things to get to that stage. I do often wish if I could get it, I would do it faithfully every day just to get a bit back"* (Mark, mid 70s, physical disability).

The wider community, and particularly neighbours, were identified by a number of participants as being important to maintaining independence and, specifically, to being able to manage in the home:

> *"And I know that sometimes I don't have a great grip. If I couldn't open a jar, I know that I could find somebody very easily. If I had difficulty with supposing, I'm not very tall and if I needed to reach up very high, I could get help from a neighbour"* (Michelle, late 50s, physical disability).

For participants like Brigit, a substantial degree of distance and independence could be maintained, while all the while knowing that helping hands in the neighbourhood were never far away: *"Anything really. There are men down there in those places I wouldn't even know them but at the same time if something happens"* (Brigit, early 80s, physical/sensory disability). Brigit also acknowledged the role of neighbours in looking out for her and ensuring that she was as safe and secure as possible. She spoke about putting in an alarm system in her home following a burglary and that had she not: *"the neighbours would have put it in for me"*. It was evident in Brigit's case that the neighbours were an ever-present factor that supported her to maintain her independence in her home and community.

The majority of participants lived alone and a minority lived in a group home or a social housing arrangement. The latter housing arrangements arguably afforded a greater degree of social interaction and support. However, it is important to highlight that even in such arrangements, independence could be maintained: *"Oh I love living in my own house. I have two keys. I lock the door at night, I don't leave it open, I lock the door at night"* (Shane, early 50s, intellectual disability).

Although participants were prepared to accept varying degrees of support from their families, in many cases their attitudinal independence prohibited them from accepting help to an extent that would, in their own view, make them feel a burden. This was justified by their belief that their families had their own lives to lead:

> *"But you see I don't want to spoil their lives you know, do that to them. Come over and mind me, come over and mind me, come over tomorrow, I want you tomorrow. They'd come, they would. Its often they'd ring me and say I'll be over tomorrow. I'd say no, don't come now tomorrow. I might want them but that wouldn't be right, ruining their lives, the creatures. It wouldn't be right to do that to the creatures. Haven't they to make it themselves"* (Matt, mid 80s, physical disability).

This preference not to impose on family members was a common assertion throughout the narratives:

> *"And I don't like asking the grandson. He definitely would stay every night I wanted him but you know you don't want to be taking that much pressure on those that has to get up for work in the morning and that sort of thing"* (Catherine, late 70s, sensory disability).

Indeed feelings of dependency were difficult to accept as some participants could imagine themselves in reversed roles. Ronan remarked of his wife: *"She sits me with a sandwich or whatever and she goes. I don't know how she puts up with it. I couldn't do it"* (Ronan, early 80s, sensory disability). Matt expressed a similar sentiment regarding family intervention: *"I wouldn't like that. I wouldn't like to be doing it to myself either"* (Matt, mid 80s, physical disability). However, participants in the main were realistic about the future and, while at times somewhat resistant to the idea of independence being curtailed, they were accepting of compromises that would allow them to retain as much independence as possible: *"And when the time comes either her or the other daughter, between them they will decide, will have to move in with me you know. And at first I didn't want that but that's the way"* (Sadie, mid 70s, physical disability).

Participants highlighted both facilitators and barriers to independence. Maintaining independence in the community was closely linked to support, services, neighbours and mobility. Services that enhanced their ability to get out in the community were particularly significant: *"Here you've got a great bus service. I'm satisfied with that even though I can't drive like a bunch of my friends. Things like that they are very important. I know I can get on the bus and go anywhere I want to…"* (Ronan, early 80s, sensory disability). Foregoing vehicular independence was nonetheless significant for Ronan, as well as the other participants: *"They took my drivers licence off me. I have no car"* (Ronan, early 80s, sensory disability).

Barriers identified related to finance, health and social capital. One participant spoke about his brother-in-law who did not have any immediate family of his own and had acquired illness in his later years:

> *"Well looking at the brother-in-law, he had no finance, he was under this and the poor old devil he was, that's where it's worth having a few bob on the side. Because if you need people and they want so much per hour, we should be able to cover that"* (John, early 80s, physical/sensory disability).

Independence was clearly an important factor in community living for participants. It was part of what it meant to maintain independence in the home and it was something that the participants wanted for their own lives: *"I think I would. I think that is what they are trying to do now, to see if they can get more* *people to stay in their own homes independently"* (Veronica, mid 70s, physical disability).

5.3.5 Independence Summary

Independence emerged from narrative interviews as a significant theme for all participants, irrespective of their particular life-course history, age or impairment. Independence was experienced and asserted differently depending on circumstances. It was articulated mainly through three avenues: identifying as independent, experiencing independence and maintaining independence. Just as independence was interlinked with resilience, the role of support in experiencing community living was also evident and will be explored in the following section.

5.4 Support

Support, both in the context of being a recipient and a provider of support, represented the third key theme to emerge from the data. It was a factor in the participants' conceptualisation of community living as well as their lived experience. Support was both a measure of participants' ability to live independently in the community and of their quality of life.

5.4.1 Case Illustration: Eithne

Gender	Female
Age	Early 90s
Disability	Physical (mobility impairment)
Marital Status	Married
Children	1
Living Arrangement	With spouse in own home
Location	Rural, residential
Professional Status	Retired business owner

Eithne, a participant in her early 90s with a physical disability, exemplified the various forms that support could take. Eithne lived with her partner, George, in a rural area, having moved there from overseas some years previously. Accordingly, Eithne did not have any family of her own in the country. Eithne's life course was marked by significant upheaval, including the traumatic loss of a close family member, assuming a caregiving role for a younger family member, business challenges, the breakdown of her first marriage, and coping with her current partner's alcoholism and deteriorating health. However, Eithne was a largely positive person who appeared to take adversity in her stride. She remained optimistic about the future and was open to measures that would support her to continue living her current life.

Eithne received support from a number of sources and this support extended beyond physical support to a more fundamental and less easily defined support that derived from her close friendships and relationships with people within her wider support network. Both forms of support are important and contributed to Eithne's overall experience of meaningful community living. Eithne's support network included professional carers, friends and people she had met though her association with community groups.

Professional Support

Eithne had two regular professional carers who had been with her for a significant period of time. She was satisfied with the level of care that they provided and the tasks that they performed to help her in the home. Furthermore, she was grateful that they were part of her life: *"I have wonderful carers. I've got the two most wonderful carers. They are my angels. They give me my shower, they look after my beds. They change the beds and put the washing in the machine and when the weather is good on the line bring it in and any ironing."*

As these particular carers had been with Eithne for a long period of time, they had formed a close bond that extended beyond the professional carer/client relationship to that of friendship. Eithne appreciated her carers' interest in her wellbeing and the help that extended into areas of her life outside the normal remit of their job description: *"Yes and she does all my, how do I explain, like see EIR and they were charging me 50 something a month. And she said 'Eithne that's too dear. You can get it cheaper.' She put me on to Vodafone but she did it."*

Eithne was cognisant of the value of carers and the positive impact that they could have in a person's life: *"Oh yes all those things, those carers, if you have a good carer, they really are carers. They really are. They are lovely people."* Furthermore, Eithne appreciated the flexibility of her carers, which added to the value of the support they provided:

> *"But to be honest, she said to me, 'I've been given an hour with you', but how can I explain this, on a Thursday she gives me my shower and does my hair. She comes about 10 o'clock and it might be 12 when she goes because she sweeps the floor or does something for me for the weekend. She's very good but as I say she comes Monday to Friday. But she might come on a Tuesday. Like today she won't come at all because I'm not there anyway. But tomorrow she might come and she might stay an hour."*

This highlights the positive effects of a more flexible care relationship. The quality of Eithne's care was not compromised by the flexible approach adopted, but rather had been enhanced though the understanding of her carers. The carers were aware of Eithne's schedule and needs and exercised some personal autonomy in how they responded to these needs. Eithne was aware that her carers went above and beyond what was strictly required and, although couched in humour, it was still evident that this was deeply appreciated: *"One comes in Saturday and Sunday, just I think to see if we are still alive."*

Social Relationship Support

Eithne, perhaps somewhat surprising for a person in their early 90s who had moved to another country in older age, had a large and diverse group of friends. She engaged socially with different groups of friends for different activities. She enjoyed playing bridge and was part of a regular bridge club. For this, she relied on a friend to provide transport: *"My friend takes me and brings me back. And always sees me in the door. It's very good."* This is significant as, but for this support, it is likely that Eithne would have given up a much-loved social outlet. However, this support meant she did not have to go to the hassle and expense of arranging transport herself. She was assured that she would be collected and returned safely home at night and this was invaluable for peace of mind. Eithne spoke fondly of friends whom she met with on a semi-regular basis to celebrate occasions such as birthdays and Christmas. Although their interactions were not overly frequent, it was evident that Eithne valued the support of these friendships, as their interactions were an opportunity to catch up on each other's lives: *"And I have two very lovely friends. We all play bridge, we all play whist..."*

Eithne also received support from the various groups that she was associated with. One such group was the day centre that she attended once a week. Each day at the centre had a regular group and in this way friendships naturally formed and were nurtured through regular contact. This group gave Eithne a sense of belonging and was an escape from a somewhat difficult and monotonous home life:

> *"It's very important. They are more important than family, friends you know because you can really, I don't know. Well I have no family as I said. I have no family. I've got nieces and nephews but they are all in England or America. I've nobody here at all, not a sinner at all. And it's very difficult. Sometimes I feel lonely and other times I feel so rich with friends because they are all friends here."*

The high value attached to friendship and the support Eithne received from this group was clearly evident. She could rely on the relationships with the regular group as well as staff and volunteers as sources of support. She knew that she could discuss issues with the staff especially, and this was a valuable avenue of support. She did not burden them unduly but the unobtrusive support they afforded by both their presence and interest in her life was appreciated: *"It's wonderful at the centre. And they are very good. That did me a lot of good."*

By virtue of her regular attendance at the day centre, Eithne had been "adopted" in a manner of speaking by the support association for the particular condition that many of the other service users had. Eithne had been welcomed into this group and was even included in their social outings. This afforded both support and a sense of belonging:

> *'So I haven't had a holiday this year. But then I got a wonderful call from {name} that was here. And she said, 'Eithne we are going to Portlaoise' and she said 'we are going on the 10th, in September' and she said 'we would love you to come with us'. She said 'you are booked in'. I said 'yes please'."*

Providing Support

As well as being a recipient of support, Eithne herself provided support, not least to her friends by virtue of her enthusiasm and positive outlook on life. It was clear from her account that friendship should never be one-sided and for all that she received vital support from her friends, it was clear that Eithne viewed friendship as a relationship of reciprocity. She also provided support to George who had advanced dementia. He did not receive any formal support and therefore caring responsibilities fell to Eithne. Although George was mobile and able to perform self-care tasks, Eithne was the person who looked out for him in the home. She assumed this role out of a sense of duty: *"As much as I have no love and he has no love but there is a commitment I think…I do worry about him."* She was also the point of contact for George's family, some of whom found it difficult to communicate with him and this made for a tense home life and further emphasised the value of external support in Eithne's life:

> *"I didn't know there could be so much hate. I didn't know there could be. I can feel it but I am friendly with all, with everybody, the whole family. They come in to see me but will not talk to him. And the other half comes into see*

> *me and they talk to him as well. So I'm all clear on both sides. I got the best of both worlds but he doesn't welcome anybody. Nobody is welcome in the house, nobody."*

As highlighted in the above narrative, support could take many forms and derive from many sources. Support was also often formulated in a reciprocal arrangement. It featured in many of the narratives and may be categorised into receiving support, appreciating support and providing support. That there was a gendered element to support was also evident in the caring roles that many of the female participants assumed and also in the sources of support that they received.

5.4.2 Receiving Support: Formal and Informal

Many participants received formal support. For participants with intellectual disabilities, support was provided through a service provider and its form depended on individual needs: *"The staff come in to give me support there because I suffer with back pain and it kills my back when I'm hoovering or mopping or anything like that"* (Michelle, late 50s, intellectual disability). These participants, now living in the community, were happy with the support they received and it was a significant factor in their ability to live independent lives in the community: *"I love it. People are nice and the staff looks after me…they are really good. They come down to see if I'm ok. If there are any problems, just ring them. And there is a nurse who looks after me; she works for the {service provider}. Yeah, she is good yeah. That's it"* (Liam, mid 60s, intellectual disability). For Liam, an important aspect of this formal support was its unobtrusive nature: *"One of them phoned me yesterday. Great to have something like that"*. Staff, present in background, could be called and relied upon should any problems arise. However, this did not encroach or undermine Liam's independence in the community and his ability to live his life on his own terms. In this way support was a dimension of his life but was not dictated by it. This subtle aspect of support was echoed in the narratives of other participants such as Joe: *"Oh it is* *handy, I can’t say I’m not being looked after”* (Joe, early 80s, physical/sensory disability).

Participants valued the informal support that they received from family. Wives or daughters most often provided informal support. The male participants acknowledged the supportive role of their wives in helping them manage their conditions and continue to engage in the community. John felt that the support he received from his wife in the home allowed him to continue to engage in the volunteering activities in the community that he loved and this added to his sense of contentment with his life: *“But then again she has great patience as I’m gone away. It takes another good person that side of it”* (John, early 80s, physical/sensory disability). Ronan’s appreciation for the love and support of his wife was reflected in his sentiments acknowledging this caring role: “*She hates to leave me alone…she sits me with a sandwich or whatever and she goes. I don’t know how she puts up with it, I couldn’t do it”* (Ronan, early 80s, physical/sensory disability).

Daughters in particular were the main providers of informal support for their parents. Participants like Sadie acknowledged that it was her daughters more than her sons who provided support, with one daughter having given up her job to assume this caring role: *“My daughter took me on, being my carer too when they found out about the situation”* (Sadie, mid 70s, physical disability). Sadie felt that this was the best situation for her and indeed had been advised to accept this arrangement by others: *“So for my own sake she said you’d be better off to let your daughter. She’s doing the carer thing for me so she is kind of my carer. So she has to keep an eye and check for me and all that jazz.”* However, Sadie also highlighted that this arrangement could change the dynamic that had existed before and alluded to feeling misunderstood at times by her daughter: *“You always need some kind of help. I don’t think people realise, especially your own family, I don’t think they realise how you feel.”* In Catherine’s case, although she acknowledged that she could call on her sons to help if need be, it was her daughter who provided the regular and practical support. Catherine’s daughter checked on her daily and helped with the shopping and household chores. John acknowledged the role of both his daughter and granddaughter in supporting him and his wife. Joe also received much informal support from his daughters in terms of companionship, care and advice. He acknowledged that he was fortunate in this regard: *"I'm awful lucky to have them. They are awful good to me, really looking after me"* (Joe, early 80s, physical/sensory disability).

Community groups, such as day centres, were also a valuable informal support, particularly for those participants who lived alone and lacked close confidants. These groups offered an avenue for discussing problems or issues, from the personal to the superficial: *"This is a great place. They are very good for helping, especially {manager}. If you want anything, if you have any problems with papers or anything, she'll sort you out"* (Veronica, mid 70s, physical disability). Such groups allowed participants to be themselves in a supportive environment: *"You see they don't feel as inferior…tell each other, that's a good thing in the group especially when we are sitting around"* (Sadie, mid 70s, physical disability).

A number of participants also reflected on the various forms that informal support took and the impact that this had on their ability to live independently. For Catherine, as a person navigating the built environment with a sensory impairment, even strangers were a vital source of informal support: *"But it's surprising what happens when you do go in and there are so many nice people out there. If I want to cross the road…I have to get help and so they stop and bring me across"* (Catherine, late 70s, sensory disability).

5.4.3 Appreciating the Value of Support

Many participants received formal care in the home. Where such care was provided, all of the participants received formal care from female care workers. They appreciated the carers that went above and beyond in the type and level of support they provided. Joe described his carers as *"a godsend from heaven"* (Joe, early 80s, physical/sensory disability). Participants appreciated the support they received from their formal networks of support: *"Oh it is very important to me to have lots of people"* (Shane, early 50s, intellectual disability). For Shane, this also meant knowing that he had someone to talk to: *"Oh I would talk to {name} now if I had a problem. I'd talk to {name} and he'd help me out then."* Frank echoed this sentiment: *"When the people that is with you, they are doing what they can for you and so on and so what"* (Frank, early 50s, intellectual disability).

Some participants acknowledged the value of having people step in to provide encouragement for them to be less isolated in the home: *"I know a woman now that was around the corner now and she wouldn't go anywhere…but now she is involved in everything because you see they roped her in nice and gently. So that's what they need, to talk to you"* (Catherine, late 70s, sensory disability). This highlights that support extends beyond physical help to a psychological support.

Informal support provided by neighbours was also important to the participants and was acknowledged as such. In John's case, he credited his successful recovery from hip replacement surgery with his neighbours who made sure that he exercised:

> *"But again I had good neighbours there. One man would be outside the door at half nine before I'd be down the stairs for a walk. Two rounds of the circle or something like that. And then in the evening another lad about half past six and sometimes at midday he would be out for a walk."* (John, early 80s, physical/sensory disability)

Sadie recognised the value of empathetic neighbours who understood the constraints of her condition and who could provide informal support to help mitigate the effects of the disability she experienced: *"I have a neighbour across the road and they are lovely because he is talking care of his own wife* (Sadie, mid 70s, physical disability).

Joanna acknowledged the importance of having formal support to manage her condition, in particular from one of the clinicians associated with her support group: *"He is at our elbow and if we need him anytime, its brilliant."* Furthermore, she highlighted the confidence that this gave her: *"When you have backup, you have more confidence"* (Joanna, late 70s, physical disability). This reinforces the importance of support in managing impairment and conditions so as to help people to continue to live independent lives.

Some participants highlighted that for others the lack of a support network could be difficult and could arise by virtue of widowhood or being a returning emigrant:

> *"And you see most people who live here, lived and worked in England or farther afield...most would have lived in dear London. {Name}, whom I mentioned being such a good neighbour, will talk about going home to London. Some would still have a network but a lot don't"* (Michelle, late 50s, physical disability).

Having a confidant was a particularly pertinent aspect of support for the participants. Dermot, although living alone and having never married or had children, knew he had a supportive network around him with whom he could talk things over. His family provided this particular form of support. It could be something serious or something simple but knowing he had a confidant gave Dermot much needed support to remain living independently: *"In other words if anything serious comes up even if it's a question of changing the car or anything like that, I'd always have a chat with them to see what they think."* In Dermot's view, the value of this type of support was immeasurable as through his previous volunteering, he had witnessed the effects of not having this type of support: *"It opened my eyes to one thing and this is that even though I live on my own and so on, if anything serious comes up I will still talk, to my brother when he was alive or my sister in law or the clan at home"* (Dermot, early 80s, physical/psychosocial disability).

Michelle highlighted the value of having an advocate to act in support of a person, especially in stressful times:

> *"Oh I see it as being very important because supposing if I need home help, and I could very easily. How do I start going around it, particularly if I'm at the place of needing one? It means that I am not as well able to get around; I am not as well able to state my case. I need to have somebody with me doing that"* (Michelle, late 50s, physical disability).

Michelle saw having an advocate as being particularly important when people were most in need of support: "But as I said before, when you are down, its not the time to be standing up for yourself to get what you know you need."

5.4.4 Fulfilling a Supportive Role

For some participants, even casual encounters were viewed as opportunities to provide support to others, even strangers. Providing support and making a contribution in the lives of others made participants such as Mark feel good about themselves:

> *"You might go into a café or restaurant or something like that and its crowded and you see one space and you sit down and the person across from you…and after maybe two or three minutes you are actually communicating with this person, you are talking and you see that they want to talk. And at the end of the cup of tea or coffee or whatever, you find that they have a serious problem and they want to talk about it…"* (Mark, mid 70s, physical disability).

For Dermot, community involvement fulfilled a wider societal role. He was proud that he had been able to offer support to a community project on the history of his former workplace:

> *"In some ways I found that it was great to be the age that I am because a lot of people that were involved in that wouldn't have been there in {place} way back in the early '70s and I was, and I was able to put them right on quite a few developments and changes that have taken place since then"* (Dermot, early 80s, physical/psychosocial disability).

Dermot was proud of the supportive role he played in this project through his contribution to content and accuracy: *"And there again I was very happy to be able to contribute to it as well. Also I say to myself that I'm very fortunate in that I have a reasonably clear sharp memory of things that happened and so on."* Dermot also saw this supportive role as extending to his involvement with younger people in the community:

> *"That's something they did here one year. They took the transition year girls from some particular school, one of the schools here in Galway. I happened to be reasonably good at physics and things like that and I used to challenge them fairly well on things like heat or light or whatever it was…if I get fellas, say apprentice electricians, I'll throw them a few 6 markers."*

It is evident that being involved with projects and students in the community was an avenue through which Dermot saw an opportunity to lend his support and in so doing give something back to the community. Providing support in this way was important to Dermot's sense of identity, purpose and role in the community.

For Michelle, providing support in the community, especially by helping her neighbours was an important aspect of her life in the community. She was happy that she was in a position to offer support to her neighbours, especially as some had nobody else in their close network. For Michelle, fulfilling this supportive role was an aspect of her identity and an extension of her professional life helping people: *"I try to be as helpful as I can in so far as I see needs around me. And I'm* *able to give time. That's what people want most of all, time"* (Michelle, late 50s, physical disability). Michelle recounted a recent scenario where she had accompanied a neighbour to hospital and had fulfilled a supportive role, helping him to communicate with the doctor and ensuring that the emergency room experience was not overly traumatic:

> *"At least that day I could be his advocate a bit and I was able to see where he could sit down. The A&E in the regional isn't the best place to spend a Sunday afternoon. There was no place that I could sit near him and he said I would be ok if I went over someplace else but I had to keep an eye to make sure he was ok. Even in helping to get the cup of tea, though they were great there for bringing around a trolley with tea but to make sure he got it with the sugar and milk and a bit of a biscuit for him, that kind of thing. He did need somebody to be with him for sure."*

Indeed, Michelle saw this aspect of fulfilling a supportive role as being part of what it meant to live in the community in the spirit of reciprocity. She regarded helping others as a natural part of community life once you were in a position to do so: *"And to make life easier. In that way there is great reaching out where people are secure enough in themselves to be able to do that."* This was echoed for Dermot, who clearly articulated that fulfilling a supportive role has always been a part of his make-up:

> *"Although at the same time I do find it easy get on with other people and so on. In fact at work if people had to be approached at say, example if they had difficult circumstances or things like that, I was always one of the people that would be always, 'Dermot can you have a chat with this one and see can you get them to do this or the other'"* (Dermot, early 80s, physical/psychosocial disability).

Dermot had also engaged in volunteering and remembered this avenue of support giving as a positive experience: *"I did actually work as a volunteer in a* *night shelter for homeless men some years back as well. And oh it was one of the best things that I ever did."* John expressed similar sentiments in respect of time as a volunteer going to the homes of older people and prior to that with disadvantaged children: *"That was great satisfaction in that you know"* (John, early 80s, physical/sensory disability).

Helping and supporting others is clearly something that Dermot values highly as an aspect of his identity and this has continued to the present time. He was proud of the fact that he is "student friendly" in the hospital and by allowing medical students to be involved in his various conditions as part of the learning process, he feels he is fulfilling a supportive role to them in a wider societal context: *"I don't want to go on all day about it but I do find that to be able to provide help to students, I find that very rewarding actually"* (Dermot, early 80s, physical disability). This was echoed by Michelle who also took pride in helping students with their research: *"You see different people like yourself do research and sometimes I say yes to participating in the research"* (Michelle, late 50s, physical disability).

Some participants had been in a position to support family members. This often took the form of helping with their grandchildren, and again it offered an important sense of purpose and fulfilment knowing that they were valued and needed:

> *"Babysit oh yeah. I've done it. {laughter} Still won't I, I love having them. I love doing things for them, the old ways. They say ma that's old school, I'm always being told. And I say there is nothing wrong with old school. Doesn't mean there is no intelligence there. There is even more as there were more listeners. As I say you'd have more listeners. {laughter} But I'd be trying to get them to play cards with me or play board games or something. Stuff for the brain as well"* (Sadie, mid 70s, physical disability).

Catherine derived a similar sense of worth from providing support through caring and teaching grandchildren:

> *"Yes they would. I can you know mind those. I have great, the smaller ones now, they are great because they listen to me. And you know it gives them a, I mean when they come in the door the first thing they say you are the best granny in the whole world, you know"* (Catherine, late 70s, sensory disability).

For Brigit, support was provided to her grandnephews by giving them free accommodation in her home: *"Two nephews went to college here for two or three years. And they were fine. They wouldn't have been able to be in college if they were in Dublin really. Being able to stay with me"* (Brigit, early 80s, physical/sensory disability).

Other participants, like Joanna, provided much support to their spouse in the home, and while this was not always an equitable situation, it nonetheless kept the participants active and gave them a sense of purpose:

> *"But its good for me and even though I give out about hubby, its good for me because I have to do it and its good for me to have to do it. There is a lady much the same age as myself in the area and her husband does everything…and she isn't one bit the better for it you know. A man like mine she'd have to manage"* (Joanna, late 70s, physical disability).

5.4.5 Support Summary

Support manifested in different forms in the narratives, both in the contexts of receiving support as well as providing support. Furthermore, support in both these contexts could take many guises and fulfil different needs of the participants. This demonstrates the multifaceted nature of support and its embeddedness in the notion of interdependence. It is a significant factor in community living and central to the lived experience of the participants. An important factor in independence, support was also linked to other themes including community interaction and home and community.

5.5 Home and Community

Home and community emerged from the research study as a fourth important theme, having significance both in terms of emotional attachment to home and place and proximity to services and supports in the community. Most participants lived alone or with spouses in their own homes, with a minority living in shared group homes in community settings. While many participants had lived in the same home and neighbourhood for a significant period of time, some had moved to their current home more recently. A unifying thread in the narratives was that length of time in a home or community was not necessarily a barometer for depth of attachment.

5.5.1 Case Illustration: Catherine

Gender	Female
Age	Late 70s
Disability	Sensory (visual impairment)
Marital Status	Widowed
Children	5
Living Arrangement	Alone in own home
Location	Urban, residential estate
Professional status	Retired homemaker

Catherine exemplified the multiple meanings that attach to home and community in the lives of older persons experiencing disability. Catherine, in her late 70s, had acquired a sensory impairment in midlife. She was widowed for some time and lived alone in her own home in an urban residential area. Catherine had close family, including adult children and grandchildren of varying ages, both in the locality and wider county. She had lived in the same home and community for a significant period of time and for Catherine this had resulted in feelings of connectedness and belonging, which she alluded to throughout her narrative.

For Catherine, being in the community had many connotations. Perhaps most importantly, being in the community meant living in the home that she bought with her late husband and in which she raised her family. This was linked to both living independently and ageing in place. In her own home, Catherine expressed that she was better able to manage her condition and minimise the experience of disability. She had made necessary modifications to habit and routine that she felt had facilitated her to remain in her own home: *"There is a lot of things now that I have overcome, like things I cannot do for myself but I keep on trying and trying until I get it. I find a way around it and it works for me."*

Although Catherine expressed contentment and comfort in her home, some of her behaviours pointed to a sense that living alone carried some unease: "*Well what I do is, to feel really good, I lock myself into my bedroom. I lock the door, so when I'm here by myself I feel comfortable with it, locking it*."

Catherine was surrounded by memories of raising her children in the family home, to which they returned as adults with families of their own. This signified the importance of the home to Catherine's identity as a mother and a grandmother: *"I have another son down the road and he has two little kids so I get on great with those now."* This was significant as Catherine retained a strong degree of autonomy in her own home and this resonated in her relationships with her family. In her own home, Catherine was still very much the matriarch and exerted influence in the lives of her family members. The fact that her young grandchildren could come to their grandmother's house and be looked after by her was very important for Catherine's sense of identity. It gave her a role and a sense of purpose through which she felt valued and needed: *"I can you know,* *mind those, I have great, the smaller ones now, they are great because they listen to me."*

Furthermore, familiarity with the locality facilitated Catherine to better negotiate the built environment in light of her sensory impairment. The neighbourhood was also familiar to Catherine and remaining there was clearly a source of comfort to her. She remembered fondly years gone by when her children's friends would call to the house, and just as her own children return, so too do their old friends and those bonds in the neighbourhood are important to her: *"The most things now that have survived is when my kids were growing up all their friends now they were interested in the soccer and in playing matches down the field there every Sunday and the boys used to call here and collect my son and even up to this day when I met them they say 'hiya Mrs {surname}."*

Catherine appreciated the links to both the past and the community that were maintained though these encounters and which gave her a resulting lift in spirit: *"They never pass me out and I stop and have a chat and they say how are you keeping now and you are looking mighty and this kind of thing you know."* The inhabitants and amenities of the community were also familiar to Catherine and she drew a certain amount of her strength to maintain her independence in the community from this familiarity and continuity:

> *"And then I meet the neighbours, the ones that can't walk fast and because of their chest problems and I get them to hang onto me for support and take them to the shop, take them to Dunnes to do the shopping and then stop when they want to catch their breath or use their inhaler, that sort of thing."*

This is indicative of the interdependence that is a feature of life and which can be enhanced through being in the community. In this way, being in the community can be a symbol of independence maintained in spite of the challenges that present as a result of impairment and consequential experience of disability. Being in the community signified routine for Catherine. Although she experienced disability navigating the built environment and had to sometimes call upon the support of strangers when in town, she nonetheless was familiar with her community. She knew the bus route to take and accordingly could still venture into town to do her shopping and, therefore, maintain her independence. This ability was born of familiarity, routine and comfort with the surroundings: *"This fits me grand. As far as getting across the road to the bus, Dunnes Stores, off the bus, across the park, into Dunnes, out, home."*

However, despite overall positive feelings about being in the community and remaining in her own home, Catherine was nonetheless cognisant of some of the more negative effects of living alone, such as loneliness. Catherine was aware that she was somewhat isolated in her home owing to the changing population in her neighbourhood and an associated lack of social interaction. She was aware of the benefits of actually being out and about socially in the community and how she was lacking in this regard: *"You meet people and you go for a cup of tea. Say come on over for a cup of tea now, you know that kind of thing. And you make friends that sort of way. I'm only friends with my house."* In this regard, the duality of home as both a place of refuge and isolation, depending on individual circumstances was highlighted.

Throughout the narratives in the research study, the significance of home and community in the experience of community living in the lives of older persons with disabilities was demonstrated. It resonated under different guises and may be expanded upon under the headings 'ageing in place', 'belonging and being needed' and 'appreciating community life'.

5.5.2 Ageing in Place

The importance of staying in one's own home was present throughout the narratives and indeed overall the participants were determined to age in place: *"Everyone likes to stay in their own home. For as long as I can"* (Veronica, mid 70s, physical disability). Home was important to them and they envisaged staying there for as long as they could*: “Oh yes, I’m going to stick it as long as I can”* (John, early 80s, physical/sensory disability).

Participants referred to the importance of the home in somewhat abstract statements, which nonetheless managed to convey the centrality of the home as both an anchor and a beacon: *“There is no place like your own”* (John, early 80s, physical/sensory disability). Home for participants like John was a place of your own where you could be yourself and live your life on your own terms. John was a sociable person who continued to make an effort to be active in the community but home was where he returned: *“In your home you are happier. People may be coming in to see you, visitors and that and friends.”* He explained his reasons for not attending a regular lunch club on the grounds that he was happier to have lunch at home with his wife*: “As you can picture you see, my wife is at home and I would call her a good cook and its much nicer the two of us sitting down together to have it.”*

The centrality of home was an important aspect of being in the community and by extension of ageing in place. Participants were happy in their homes: *”Oh I love it. It couldn’t be better”* (Joseph, late 70s, physical/cognitive disability). The participants wanted to remain living in their own homes: *“Oh I’m very happy. I’m happy where I am. I love the house, it’s a beautiful house so it is. It’s a lovely house”* (Shane, early 50s, intellectual disability). Although participants were universally determined to age in place in their own homes, some like Joe expressed similar sentiments to Catherine, which served to acknowledge the loneliness that home could also represent: *“Oh I’d stay there. I’d stay there. The only thing is I don’t like living alone. I hate it. I was never used to it”* (Joe, early 80s, physical/sensory disability). This was especially apparent for participants like Joe who had experienced the loss of a spouse and for whom home signified both connection and loss. Indeed, for many participants, ageing in place brought with it the reality of change and loss: *“So many changes. People moving in, moving out, people dying”* (Michelle, late 50s, physical disability).

5.5.3 Belonging and Being Needed

For a number of participants, remaining in their own homes also meant continuing in the roles that they had become familiar with in their families such as providing support or care. This was particularly evident for the female participants, such as Joanna, who, despite her physical disability, continued to look after her husband, as this was ingrained behaviour:

> *"My husband can't even hardly boil the kettle. Stop don't start me. And he came from a family of twelve you know. You know and you'd think he would, you see the men back then were outside of the home and did whatever job they had, and they worked outside. The woman, they say a woman's, I was in for a brain scan there and the fella in the hospital and the doctor said sit there for an hour and don't move. I had all these things in my head. I said I don't know when I sat for an hour before"* (Joanna, late 70s, physical disability).

Joanna's son had arranged for a trial meal delivery service in order to make life easier for her. However, her husband was resistant to change and so Joanna continued to cook: *"I got it for two weeks and hubby wouldn't eat the dinners. And then there was no point in me getting the dinner because then I'd still have to get his."* Despite Joanna's gentle chiding of her husband's lack of domestic efforts, it was evident that she was content to continue to take responsibility for the household tasks: *"But its good for me and even though I give out about hubby, its good for me because I have to do it and its good for me to have to do it."*

Participant Finula, whose brother had moved into the same apartment complex as her, echoed this sentiment about the importance of being needed. Finula took care of her brother, helping him with household tasks and cooking his meals and like Joanna, this offered a sense of purpose:

> *"Now I have a brother next door who had a quadruple bypass and he has every other ailment under the rising sun. But he's the greatest, most untidy person in the world, not just in the west of Ireland but in the whole of Ireland and I do his dinner every day. And tidy up for him. And home help comes in to change the bed because it would be too much for me. So that occupies me"* (Finula, early 80s, physical/sensory disability).

Finula, by virtue of maintaining her independence in her own home in the community, was also able to offer support to her wider family, especially in recent times of tragic loss. She derived a sense of purpose from this supportive role and felt valued: *"I do feel important to them. I'm important especially to my sister-in-law."*

Having roots in the community was also important to the participants and time was not always a measure for the depth of these roots. This was particularly relevant in the case of participants who had more recently moved into the community, but nonetheless found a place to call home and to which they demonstrated attachment and a determination to stay. Having a sense of belonging in one's community was important to participants such as John who had returned to Ireland in midlife having worked for many years in England. He settled into a residential suburb of Galway city and found his place in the community: *"Oh yes, ah yes, we found our own rhythm"* (John, early 80s, physical/sensory disability). This was echoed by Ronan, who was not from Ireland but who had met his Irish wife and eventually settled in Ireland with her, laying down roots and making a home: *"We used to date together and then when we got married, then we bought a house here so that's why we're here in Galway"* (Ronan, early 80s, sensory disability).

For participants such as Sadie, having a sense of belonging was very much linked to being in the community. In her own words, Sadie had moved to Galway for love and having tragically lost her husband suddenly some years ago, the home they built together still anchored her despite her loss:

> *"So we built up a home together, me and my husband over that time. And then you know we kind of did, kept the house done up and it was always his motto that the woman, the woman looked after the house and that the father provided you know. I suppose in today's world it could be vice versa, the other way around but he did a lot, he did a lot with the house and we ended up very nice neighbours over that time"* (Sadie, mid 70s, physical disability).

Sadie felt a deep sense of belonging in her home and community that she had moved to with her late husband and where so many happy memories resided. She had become a mother in this home and was proud of the life she had led as a wife and mother. Although her husband was no longer with her, his presence was felt throughout her narrative.

Participants such as Frank had more recently moved into the community. Having lived most of his life in a residential institution, living in the community offered more opportunity: *"You can do what you can do now in the wintertime when you are out in the community"* (Frank, early 50s, intellectual disability). Furthermore, Frank felt a sense of attachment to the community that he now called home and had found a place to belong through both his professional and personal engagement with the community. He was happy with the town and its inhabitants and felt content: *"It is a nice town"*.

5.5.4 Appreciating Community Life

Community life was appreciated for all that it offered in terms of opportunity for social interaction, access to services and supporting independence. Participants appreciated their neighbours and the community spirit that existed:

> *"There is, not as I said among everybody but there is a great group. One person who came here, for the last I suppose, he must be here four or five years now, he just added so much to the place. It's amazing what one person*

> *can do…he would be looking out his window to see if you needed helping bringing up your bags and he would be there. He would nearly be giving out to me if I didn't ring him to say look I have a lot of things, will you help me"* (Michelle, late 50s, physical disability).

Michelle expanded on this reciprocal nature of community living that echoed the interdependence in Catherine's narrative: *"I am certainly appreciating more and more that thankfully I know everybody's name here…and I know that if one person I meet has a difficulty that I can't answer, I can ask someone else here to help out. So yeah it's give and take."* This sense of community in the neighbourhood was repeated throughout the participants' narratives and is most certainly one of the strongest advantages of living in the community rather than in residential care for older people with disabilities. Participants such as Brigit acknowledged and accepted that some people kept to themselves in the neighbourhood but, overall, the sense of community spirit was present: *"Now there are people that will keep to themselves. But that's the way they like to live. But not this end of it"* (Brigit, early 80s, physical/sensory disability). Brigit was proud of the sense of community that existed in her neighbourhood and this quite clearly augmented the satisfaction she felt being in the community. Some participants cloaked this sense of community solidarity in humour but it was still evident that it was deeply felt and appreciated: *"But we're all getting older, visiting one another more often to see are you there at all"* (Joanna, late 70s, physical disability).

Participants such as Veronica highlighted how there was always something happening in the community: *"Then we have a film night on Wednesday nights. What else do we have, art every week. What else do we have, there is always something going on anyway"* (Veronica, early 70s, physical disability).

Participants also appreciated living in their communities for amenities such as a regular and reliable bus service and proximity to retail and social outlets: *"The services are good and the church is right across the road. That's a lot. Then the* *shops are quite close by…and there are two post offices and a bank. What more does a person want"* (Veronica, early 70s, physical disability).

This sentiment was echoed by Ronan, who appreciated familiarity in the community where the local bus drivers recognised him and made him feel more confident negotiating the public transport system: *"And you know I get on the bus and I have the pass in my hand, go ahead, go ahead. You know he never makes me wait or anything, puts me on the bus. They don't seem to mind it at all"* (Ronan, early 80s, physical/sensory disability). Veronica also appreciated the services that were in her locality that made her life easier to manage and assisted her in maintaining her independence: *"I used to have to go across the city to get to my doctor. I decided last year, why am I doing that when I could only have to go across the road. It's very handy. And they are nice"* (Veronica, early 70s, physical disability). Brigit was extremely satisfied with the local bus service and medical services in her locality. She acknowledged that living independently in the community afforded her choice: "*The services are very good. I mean the community care service and GP service. A variety of GPs, if you don't like someone there are many of them around"* (Brigit, early 80s, physical/sensory disability).

Overall, participants appreciated being in the community for all its advantages in terms of social interaction, facilitating independence though services and supports and affording a sense of belonging. Participant Frank succinctly epitomised what life in the community meant to him: "*It's a good life*" (Frank, early 50s, intellectual disability).

5.5.5 Home and Environment Summary

Home and community signified an opportunity to age in place in a familiar environment and this afforded both comfort and security. In familiar places and spaces, participants were better able to manage their disability and maintain their independence and autonomy. Home and community also offered a sense of belonging and of being needed. As participants had the opportunity to maintain their independence in their own homes and communities, they were in turn able to support friends and family members within their social network. From this the participants derived a sense of purpose and meaning in their lives. This undoubtedly fortified them and helped them maintain their sense of self despite experiencing disability. Finally, home and community was deeply appreciated by the participants for the opportunities it presented in terms of social interaction, access to services and promoting independence. The opportunity and diversity afforded by virtue of living in the community was central to living and ageing well in the community.

5.6 Social Interaction

Social interaction emerged as a fifth significant component in both the conceptualisation and the lived experience of community living. This is perhaps not surprising given the importance of social relations to overall wellbeing and the growing awareness of the negative effects of exclusion, isolation and loneliness amongst both older people and persons with disabilities. Its significance is also not surprising given that community living encompasses both the elements of living independently and being included in the community. The narratives confirmed the centrality of social interactions to the concept of community living.

5.6.1 Case Illustration: Brigit

Gender	Female
Age	Mid 80s
Disability	Physical (mobility) and sensory (hearing impairment)
Marital Status	Single, never married
Children	None
Living Arrangement	Alone in own home
Location	Suburban, residential estate
Professional Status	Retired professional

Social interaction played a central role in the narrative of Brigit, a participant in her late 80s with a physical and sensory disability. It may be viewed as a significant component in both her understanding of what it meant to live in the community as well as her lived experience of community living as an older person with a disability. Brigit lived alone in an established and well-maintained residential housing estate in a city neighbourhood, having moved there after retirement. She had never married and did not have children. She had a long and successful career as a professional with experience working in local communities. Work and volunteering had featured throughout her life and these experiences were interwoven throughout her narrative. It was evident that she had been committed and dedicated to her work and that this has shaped her views and attitude in older age.

Interacting with Groups

Group membership was an important avenue of social interaction for Brigit as she was a member of a number of local organisations, including retirement and drama groups. She highlighted the social aspect of her local Active Retirement group: *"And the different clubs, I mean the retirement, the different retirement associations are very helpful. I belong to one of them and it is very well attended. It is a great outlet and we have outings to different places."*

Brigit also credited the church in her community with doing much in terms of promoting social interaction through the various initiatives it employed to bring people together socially:

> *"Well I think the church has done an awful lot. They have put on tea parties. They have the activities…they have a youth choir, they have card games, scrabble and other cards and a men's shed project, a parish discovery group, morning Monday music groups…it's just a matter of having an interest. The church has put on a lot of those. There is no reason but maybe people don't maybe want to go. You don't know."*

Brigit also exhibited a keen interest in the arts, regularly attending drama productions: *"I'd go to the pictures quite often but I don't know really, the occasional one, the theatre would be more my line. We were there the other night…two episodes, totally different, it was hilarious and there was a meal served as well."* She also had membership with the local drama association: *"We get joined up to the club down there and they send you the notification and the book and you have the plays for the year in it."* In this regard, she also credited the role that the community groups played in keeping her updated and connected with what was happening in the community:

> *"Oh yes. And they keep you updated. You'd see something on a paper but you don't think about it you know. At these meetings somebody will make a comment they've been, you know theatre…anything that's on worthwhile, I go. I even have gone by myself."*

This highlights Brigit's determination to remain socially active at this stage in her life by continuing to take an interest in activities in the community.

Being Socially Active

Perhaps owing to her professional experiences of working in community settings and volunteering, Brigit was cognisant of individual responsibility to remain socially active and engaged in communities: *"I think it's up to people themselves*." Given the multitude of social outlets in the community, she believed that loneliness could largely be avoided:

> *"There is no reason to be lonely. That's what I do say. I mean there is a group over in Westside as well. I haven't been to it but I know it's there. And they play bridge during the day. And the different retirement groups do visitation to different places of interest and even though that you may not belong to it, the fact that you do belong to one retirement group, you are covered by*

> *insurance if you want to go with some of the others, as long as you are invited."*

This demonstrated Brigit's awareness of what was happening in the community and from her perspective the opportunities to be socially engaged were not lacking, however the impetus to act on them might be for some people. Brigit admitted to retirement being a wrench in her life and that she found it difficult to adjust to the new reality. In fact, motivated by this restlessness, she found alternative work for a few years post-retirement. However, injury and illness forced her to give this up:

> *"I found a big change when I retired. I missed work terribly. Routine and I found it hard to create a routine for myself. I went back to do some private work for a short time…and I did that for two years but following that I had an accident on ice here in Galway two days before Christmas and sustained a fractured pelvis. Was in hospital and nursing home for three weeks altogether and then convalesced at home and got back into a type of routine but didn't have the same energies that I had previously."*

Brigit referred to the change of pace that she experienced after her accident and other health issues*: "Just got back into a different, a slower lane of life, definitely a slower lane."* However, she was determined not to give up all aspects of the former life in the community and volunteering filled a void for Brigit at this time, which she credited as socially beneficial:

> *"And found help as regards socially there were an awful lot of clubs. I was, I volunteered for Vincent de Paul. And that was a big help because I was able to go to the meetings and be involved in visitation. I had collections as regards Simon and what's the other one, the Women's Rehabilitation down there just opposite the Town Hall. I used to go in there; there were women that were abused. They were living there at that time so I got involved with visiting there."*

Brigit admitted to missing the social aspect of activities like golf that she had to give up as a result of her impairments: *"Oh the physical activity first and after that there was a social aspect to it too. Different groups used to go out, four of us that always played together, enter a little competition."* Indeed, Brigit expressed wistfulness for these former activities: *"As years go on you know, when you are confined to barracks to a point. I mean I miss the golf so much, I did. I went to {golf club} with two neighbours and played nine but I would be afraid of it now."* However, awareness of this void in her life motivated Brigit to take up new hobbies: *"And I started to play bridge. And that was back to school type of thing, learning to play it. I then joined up with bridge clubs, playing maybe twice a week."*

Interacting with Others

Brigit interacted with others, not only by virtue of her involvement with various clubs and associations, but also through more personally acquired relationships and connections. She spent time with her family, none of whom lived in the locality, thereby maintaining social links to both people and place through these interactions: *"And weekends away. I have a member of family in Dublin and I'd go for the weekend or longer than the weekend sometimes. And go down home and spend some time down there. More or less weekends that I would go down and come back."*

She also maintained social connections with former colleagues and the people with whom she volunteered in various organisations over the years, and again this anchored Brigit to a time in her life that she remembered with fondness and pride: *"And I was really in contact with an awful lot of people in the community where I had worked. I would meet up with some of them; have a cup of coffee. No definite ties with them but they were lovely in the area that I had worked in."*

Brigit highlighted the importance of these social interactions to overall wellbeing and indeed felt that attitude played a part in the personal motivation required to put oneself out in the community and perhaps overcome natural fears relating to acceptance:

> *"I know there are problems, don't have a reason for being able to mix…you might not feel accepted maybe sometimes and you're sensitive about something but you can't let that; it can be your own doing or your own way of thinking. The people that you thought didn't accept you that might not be true at all."*

Echoing many elements of Brigit's life course, social interaction was demonstrably important throughout the narratives. This is further explored under the headings of *experiencing social interaction*, *taking responsibility for social interaction* and *appreciating social interaction*.

5.6.2 Experiencing Social Interaction

Groups

Like Brigit, many participants belonged to local community social groups such as drop-in day centres and lunch clubs. For some, like Eithne, these groups offered much needed solace and companionship: *"Well this is my community living. I live for Mondays. Because when I go back today at 4 o'clock I go nowhere until next Monday. I have people that call to see me occasionally, not every day"* (Eithne, early 90s, physical disability). Indeed, Eithne delighted in the friendships she had made at the day centre: "*Oh yes they are lovely…and I love them all. I look forward to it."* Joanna also highlighted the friendships she had made through coming to her day centre as a motivation for her continued involvement: *"But I love the crowd so I keep going here"* (Joanna, late 70s, physical disability).

Most participants had been introduced to their groups through contacts in their existing networks. Ronan described his first interaction with the local day centre manager: *"So when they asked me if I'd stop in to see this girl, I said sure and these are the fellas that I bouled with. Gee and they haven't left since the day I came in.*

And she said to me, come in and sing. Gosh she is as good as gold she is" (Ronan, early 80s, physical/sensory disability). Eithne had a similar experience, having been introduced to the service by her partner's nurse in geriatrics, who felt that she needed a social outlet in the community: *"It was just before Christmas and I came with {name} and we had a wonderful time. It was at the {hotel}. Oh it was wonderful. I had a great time. I thought this is too good to be true* (Eithne, early 90s, physical disability). Eithne clearly took much joy from her involvement with this group and described it in such terms: *"It's lovely. It's really beautiful. It's like coming home here. It is really lovely."* Ronan expressed similar satisfaction as the day centre offered him an opportunity to engage in his favourite pastime of singing. In this he felt he still had something to offer despite his impairment and experience of disability: *"Oh one day a week, Thursday, every Thursday, I come and I sing"* (Ronan, early 80s, physical/sensory disability). This opportunity to interact with others allowed Ronan to maintain a sense of purpose and value, which was important given his other losses of independence.

Active Retirement groups were frequently mentioned as important social outlets: *"Active Retirement and those clubs, I spent a few years with {place name} and then more people were getting older in our parish and we founded our own club and I came to be chairperson of the club"* (John, early 80s, physical/sensory disability). Dermot also highlighted the role of these centres as social outlets: *"As I say while a lot of people mightn't drop in, they still know it's there and they know that we are open if anyone wants to drop in or make enquiries about anything, so at the same time it does function as a social centre"* (Dermot, early 80s, physical/psychosocial disability). Some participants echoed Brigit's sentiments about the social role of the church: *"I got very much involved with the church, especially after I retired"* (John, early 80s, physical/sensory disability).

Support organisations, of which participants were members by virtue of their respective conditions, were also important. Joanna was particularly pleased with the organisation for its social aspects, which were also present in other organisations which she belonged to: *"We have an outing every year. We have*

Christmas lunch. And I have great friends in {association} and in the day centre and in the ICA (Irish Countrywoman's Association) in my neighbourhood. So I'm very lucky really" (Joanna, late 70s, physical disability). Joanna appreciated organisations' social outings:

> *"I was in the zoo early in the year. I used to bring the kids to the zoo. We had a fantastic day and we had even somebody made lovely buns and muffins and when the trolley came round we had different stuff. And we had lunch at the Aisling (hotel) and then we went to the zoo and we had more cakes on the way back. It's absolutely great. It's terrific you know. It's great to know you have that like* (Joanna, late 70s, physical disability).

Fundraising activities organised by the support groups were also important social outlets: *"That's what we were doing last week. I did the walk anyway and I've done it another time, we did another one. We always have every year we have a weekend away and that is coming up in September"* (Sadie, mid 70s, physical disability).

Community Activities

Hobbies were important to participants for their sense of purpose: *"Well I have plenty to do because the hobbies. I'm in a writers club and I paint shell pictures"* (Finula, early 80s, physical/sensory disability). Hobbies were a valuable outlet for the participants: *"We have creative writing on a Thursday…do a cooking class over in {place} on a Tuesday* (Frank, early 50s, intellectual disability). For participants like Dermot, hobbies were deemed appropriate for the particular stage of their life course: *"Right the other thing that I do then is because of my age and so on like that, I like a game of cards and I used to play bridge for a number of years as well"* (Dermot, early 80s, physical/psychosocial disability).

Community activities were important avenues through which social interaction could be facilitated. Participants such as Shane expressed how they signified the freedom that came with living in the community: *"I love doing greyhounds too, the greyhounds on a Tuesday"* (Shane, early 50s, physical disability). However, for

Ronan some activities including golf had been left in the past owing to his impairment: *"Oh no I can't, I tried twice. The first time I played about three holes and the second time I didn't even go out. I went to the club but I just sat talking and they knew that wasn't for me"* (Ronan, early 80s, sensory disability). Ronan had also given up his regular involvement with a singing group as it had become too much for him in light of his disability: *"I used to go in the same place on a Thursday, on Fridays. I was singing there with a singing group. I went every Friday for a long time and then I stopped. It was a little too much."* Joe had a similar story to tell: "*The shooting now is the problem with the eyes. I have an awful problem with the right eye in particular. What harm but I was a good shot when I had the use of them but I'm going to miss all that now, unless the eyesight improves like"* (Joe, early 80s, physical/sensory disability).

However, both Ronan and Joe continued with these community activities despite experiencing disability. For Ronan, singing, albeit on a more casual basis, and boules, remained important for social interaction: *"I still do the boules. I know where to stand and where to throw it"* (Ronan, early 80s, sensory disability).

Friendships

Some friendships had formed though the participants' involvement with groups while other friendships were based in existing networks: *"And every Sunday morning I'm picked up by an old friend of mine…He used to pick me up every morning. He didn't pick me up now this morning because I told him where I was coming"* (Joe, early 80s, physical/sensory disability).

Spending time with friends was referenced by many of the participants as being an important part of their life in the community and could be something as casual as going to the local pub at the end of the week: *"We go to {pub} Friday night"* (Shane, early 50s, intellectual disability). Social interactions with friends served a purpose in the participants' lives as a connection to the wider community. Furthermore, they motivated participants to have an interest in things outside the home and in turn ensured that others took an interest in them.

In Eithne's case, friendships formed in a bridge club extended beyond the regular bridge season to other social interactions:

> *"I'm in April so we have birthdays, so four of us go, whoever's birthday it is decides where we are going, and the other three pay. And it's lovely. We have been doing it for about seven or eight years now and it's great fun. We won't see each other now until next April because there is April and there are two in August and one in June. No, {friend} said, we will see each other before that because we are going out for a meal the four of us. We will go out for a coffee or a cup of tea or something. The four of us must meet. So anyway we go back to bridge next month in September"* (Eithne, early 90s, physical disability).

Other participants spoke of holidays with friends as important aspects of their lives in the community: *"There are three of us going"* (Shane, early 50s, intellectual disability). Michelle enjoyed social interactions with neighbours in her apartment building:

> *"Oh there is and that's the great thing about here and that's why I was telling you about Wednesday morning, the coffee morning because we have a communal area where we can have that, and it's just again somebody gave us the table around which we sit. It's a large table and whoever comes, comes for that"* (Michelle, late 50s, physical disability).

These interactions were further fostered by the design of the building with communal spaces offering potential for casual social encounters:

> *"Yeah and in that common room downstairs, there is a radio that is usually on at Midwest. In the evening time it is still on. I usually turn it off. But it is a place where somebody could wander in and sit down and you never know who you are going to meet. The foyer is great. There are two chairs if you noticed in the foyer and there are two in the outer hall as well and if you are*

> *waiting for somebody or if you passed through somebody might be sitting there and you get the few minutes chat"* (Michelle, late 50s, physical disability).

Social interactions sometimes arose from formal care situations. Eithne's relationship with her carers had evolved beyond a purely professional arrangement. She looked forward to their visits as valued social interactions: *"The girls are wonderful, they really are. One comes in the morning and the other comes in the afternoon"* (Eithne, early 90s, physical disability). Indeed, Mark alluded to the potential of homecare as a mechanism for social interaction: *"It should be built in that you are also doing a social visit. I would like them to be thinking like that. This is a social visit as well as a home help role. Put the two into one, that's my view"* (Mark, mid 70s, physical disability).

Family Interactions

The role of family in social interactions was significant and readily apparent in the participants' accounts of their lives in the community. In many cases, families were the constant in the participants' lives and the relationships, though often complex and muddled by caring dynamics, were for the most part good.

5.6.3 Taking Responsibility for Social Interaction

Like Brigit, other participants alluded to their responsibility to remain socially active, especially since they came to experience disability. For some, like Sadie, this meant joining local support groups and putting themselves out there so to speak: *"So thank God I am still here anyway. I do my best. I joined the Galway {association}. I must be in it about at least four years, at least I think. My life changed…"* (Sadie, mid 70s, physical disability).

For others, such as Ronan, it meant continuing, to the best of his ability, the activities that he had previously enjoyed: *"I still boule because it's nice. You are always with a nice crowd of people. We go way down on bus rides and stuff. We go* *to Westport and places like that. And they always get me to sing. They don't have to coax me"* (Ronan, early 80s, physical/sensory disability). Indeed, Ronan was prepared to put himself out in the community so as to maintain a connection to something he loved and this was important in light of all he had lost as a result of his disability: *"The fella who does the singing in church sometimes he comes in ok and he is great. I know I'm out of his class but I don't care. I love to sit there and listen to him sing. It's great fun."* This was echoed by Joe who was also determined to continue to engage in much loved pastimes with friends: *"If I'm alive next Sunday morning, we'll meet again. No big session, we'll have a couple of drinks and a nice long chat about fishing and shooting"* (Joe, early 80s, physical/sensory disability).

Dermot had taken up a hobby in order to avoid the negative impacts of spending too much time alone at home following retirement and he acknowledged his motivation as such: *"I play roulette as well and I can do quite well on that as well. There again it's mainly for the social contact, it's not for the amount of money that I might hope to win and lose"* (Dermot, early 80s, physical/psychosocial disability).

John highlighted the efforts that he made to interact socially with friends and how it would be easy to stay in comfortable seclusion but for making the effort:

> *"And we return the compliments, we don't always stay in the house. Only this week we were out three nights in the week. Out to Salthill there to see a couple and down last night to see another pair. Things like that but that's part of it because my {wife} now, herself she's now and I don't be too keen on it, she'd be there like this with her footstool at night and two feet up. Now she does this word, find the word you know and it's good, nothing wrong with that but you look over and {mimes sleep}"* (John, early 80s, physical/sensory disability).

Joanna echoed this, alluding to the importance of staying socially active, especially post-retirement:

> *"And I find it hard in retirement, with me and hubby anyway because I think he was so used to working and working that he expects the same things should go on you know. And it's very necessary to go and mix and have your friends and be able to give you a break from it all"* (Joanna, late 70s, physical disability).

Furthermore, Joanna made an effort to keep in contact with her extended family through regular visits: *"And they would come for the cup of tea because we lived at the back of {place} and it was central and as a result even though there were big families back then I know every one of my cousins and visit them. And they visit me. So it's lovely."*

Participants such as Catherine felt that there was a desire on the part of older people in the community to be more socially active if only the resources were in place to afford them the opportunity:

> *"I'm telling you there is an awful lot of old people around here that would love to go down there dancing if there was a little bit of music. Anyone with, you know, music, radio, plug it in. We'd all bring our own CDs. And sit down there and have the chat"* (Catherine, late 70s, sensory disability).

However, Ronan echoed Brigit's assertion that the infrastructure for social interaction was already present in the community and it was more a matter of people themselves making the effort to use it: *"Oh, they are great, if people only would enjoy it. Even just to try it, once they try it, then it's up to them. Most of them do, they enjoy it"* (Ronan, early 80s, physical/sensory disability).

5.6.4 Appreciating Social Interaction

Linking social interaction to wellbeing

Many participants linked social interaction to overall wellbeing. This was particularly evident in the context of community groups: *"Oh this is great, I hope nothing ever happens to it, this is great"* (Ronan, early 80s, sensory disability). Joanna strongly believed in the importance of mental stimulation in older age and highlighted the value of community groups in serving this purpose: *"Oh yeah and to be happy like, to know that you'd never get bored"* (Joanna, late 70s, physical disability). For Dermot, attending the local drop in centre was very much linked to his wellbeing as he valued even casual encounters:

> *"Then as well as that, here locally in {place name}, they have a drop in centre. I find it worth a lot to me as well even though the most thing that I do when I come in here is I use the Internet. It also gives me a chance to have a chat with other people during the day; to catch up on we'll say the local news. Then we'll see the other interests that we might have in common, even maybe to give out about government policy or to catch up on the matches and all the other things like that that people chat about"* (Dermot, early 80s, physical/psychosocial disability).

Dermot could recall the negative effects of social isolation in the period following his retirement:

> *"The other thing is that for a period of time after I retired, even though I have a great interest in computers and I read a reasonable share, I did spend a bit too much time at home at the house on my own and it was not doing me any good you know. There is no doubt about it I was suffering from that. So it's only since I made that change and got out a good deal more, which I do now. Then you know I find that is the only thing to do."*

John related activity and being socially active to positive health: *"There is an expression, inactivity kills. The worst thing of the lot is your remote control and sit down there day after day. Believe you me at the end of that you shorten your life. Getting up and moving around and you're keeping, keeping yourself more fit"* (John, early 80s, physical/sensory disability). Furthermore, he believed that by keeping active and interacting with others socially, he was potentially warding against conditions such as dementia: *"Dementia, that's where I would say and think if you keep your mind busy by keeping active it will not set in near as quick. I'm very much for that. By God that's why I get out and go around and talk. But the day you sit down with the remote control..."*

Joanna echoed this: *"Because you could find out if I stayed a week at home without going out to meet somebody or that, you'd really need the stimulation"* (Joanna, late 70s, physical disability). Indeed, Carmel saw community outlets as breaking the monotony that might otherwise set in staying at home: *"I suppose you have somewhere to go to. You get bored just sitting looking at the four walls"* (Veronica, early 70s, physical disability).

For a number of participants, maintaining social links with their former colleagues was important:

> *"We meet up even though we have left. They people who joined up in {community area} and we meet about three times a year, before the Races, Christmas, and around Easter. Go to {hotel name} for a meal, good old chat about different people who have got married and had families and all the rest of us, a big cross section of professionals you know. It wasn't all medics at all. We still meet you know"* (Brigit, early 80s, physical/sensory disability).

Liam also maintained social links with his former colleagues by calling into his previous workplace to catch up with them on a weekly basis: *"Oh I do, I was down in the shop last week to see them. I won't go this week now as I have to get my teeth cleaned"* (Liam, mid 60s, intellectual disability). Dermot also maintained social links with his former workplace and colleagues and stressed the personal benefits of this:

> *"I used to use the dining room in {former workplace}, the staff dining room, all the time when I was working or nearly all the time, and even yet I'd still go for lunch to {former workplace} three or maybe four days in the week. That does a lot of good for me because I meet people that I used to work with and saw the various changes in society and attitude"* (Dermot, early 80s, physical/psychosocial disability).

Participants were cognisant of the personal value of social interactions, be it having someone to talk to or engaging in an activity that continued to bring them joy. For Ronan this was singing: *"So I just sing. I sing for myself but I sing for everybody else too, you know. When I go to a pub, I say 'can I sing a song?' Its awful (laughter)"* (Ronan, early 80s, sensory disability).

Changing social interactions

Participants reflected on changes in social interactions over their life course, changes not always for the better such as in neighbourhood interactions: *"But in the early years up until the 80s I knew everyone. There are 18 houses in a circle. Hello Jimmy, hello Mary, hello Tommy. Nowadays they look at ya. It's sad I think, to me it's sad"* (John, early 80s, physical/sensory disability). They also reflected on changing family interactions: *"Now my children and my brother's and sister's children barely see one another. Nowadays it's so different. The world is so changed"* (Joanna, late 70s, physical disability). Participants remembered past community interactions fondly: *"There was, years and years ago. They used to have a little dance down there in the community centre when it first was built. They did, they had that and that was lovely"* (Catherine, late 70s, sensory disability).

Changes in social interactions had also arisen as a result of the participants' disability, as in Ronan's case: *"You know they knock on the door and they come in, that's good, fine with me but I don't know what to do when people come in* *anymore. I just don't know what to do. Offer them coffee? I can't do that because my wife has to do that"* (Ronan, early 80s, sensory disability). Catherine expressed similar sentiments: *"I'm not involved with the community as much as I'd like to be and I think its because of the vision you know. I feel kind of once I get in with a group I'm fine but it's getting there so I do my own thing"* (Catherine, late 70s, sensory disability). Catherine felt that her disability and need for support precluded her from engaging with community groups as much as she would like:

> *"I know the Ladies Club now they go to Knock once a year and I go with them on the bus. But I haven't gone now for the past, I didn't go last year now because, the women that was going I didn't know any of them personally. You know from the area and I felt like I can't, I can't do it on my own, I can't. And so I asked them could I bring someone with me and I could if I paid for their ticket like you know. That was alright but I didn't go last year because I couldn't find anyone to come."*

Ronan expressed similar sentiments about his ability to interact with new people as a result of his disability: *"It's hard for them to get to know me because I don't like to impose on. But my wife, she's, she's gotta meet people and talk to them and she's really social. Most of the time I stay in the house."*

Participants noted the fast pace of modern times that left little time for social interactions: *"Yeah everyone is in a rush. It's not like back then. And we hadn't the facilities or the mobiles or the communication that they have now you know"* (Joanna, late 70s, physical disability). Dermot noted these changes in his former workplace that he himself still frequented as a means of social interaction:

> *"{Workplace} is no longer the great big friendly place it used to be when I went there first, where a lot of people used to live in and so on. Now everybody lives out and is in a rush home and so on. The only social contact they make is maybe at work, at breaks or at lunch and that is basically it"* (Dermot, early 80s, physical/psychosocial disability).

However, Dermot also highlighted that not all changes were negative and indeed some had actually improved social interactions:

> *"If I take my sister-in-law since her husband passed away. She is in the house on her own but at the same time she would have at least three or four conversations in the night with other people. Then somebody might call but if they don't someone will ring and say did you hear there that and the other. So they don't actually meet up."*

5.6.5 Social Interaction Summary

There was a gendered dimension to social interactions. Female participants were more enthusiastic about group membership and group activities than male participants. Women spoke of the friendships that had grown from these initial encounters and the support and positive aspects of these relationships were evidenced in their narratives. The male participants, on the other hand, were more likely to attend such groups for the company rather than the companionship they might offer. Men attended these groups as a means of getting out of the house and to have something to do or to catch up on news. However, their deeper and more personal social interactions tended to come from encounters with close friends, such as Joe's fishing/shooting friend or the good friends in the neighbourhood that took John walking after his operation.

Evidently, social interaction could take different forms and serve different purposes in the lives of older persons with disabilities. It was clearly an important component in community living as demonstrated by the participants' narratives, which shared much commonalities of experience.

5.7 Chapter Summary

This chapter has focused on the main findings of the community interviews comprising Phase One of the research study. The aim of these interviews was to capture the perspective of older persons with disabilities on what it means to live in the community with a disability. These were life-course biographical interviews adopting a constructivist grounded theory approach. The benefits of an inductive approach were demonstrated as this allowed for articulation of 'voice'. The essential components of community living, as conceptualised by the participants, centred on resilience, independence, support, home and environment and social interaction. Highlighting each of these findings through a case illustration and expanding upon them more generally across the data set has demonstrated how these components are experienced in the everyday life of these community dwelling older persons with disabilities. The components have been demonstrated as interlinked and interwoven throughout the participants' lives in the community. In many respects these findings are corroborated by the stakeholder interviews, comprising Phase Two of the research study and addressed in the next chapter.

Chapter Six

Findings Phase Two - Stakeholder Interviews

6.1 Introduction

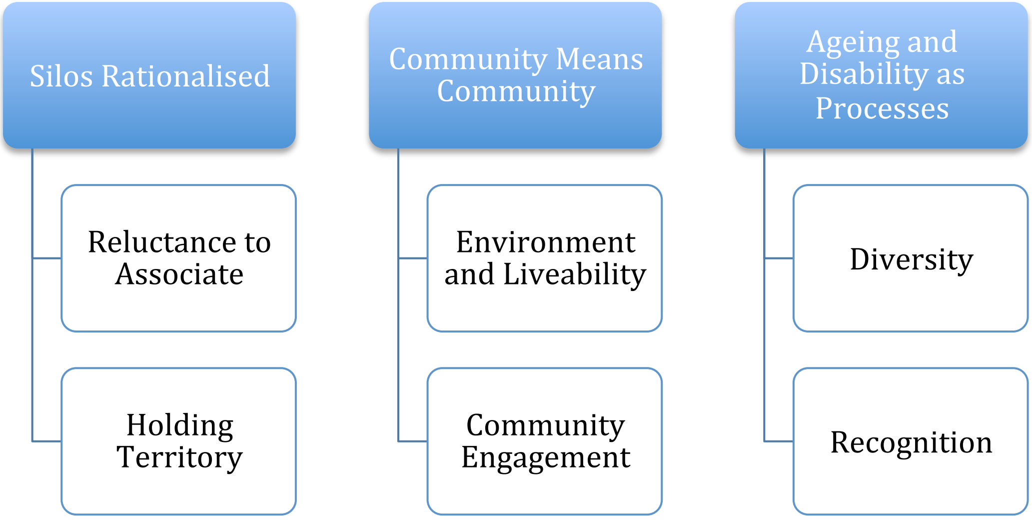
The purpose of the stakeholder interviews was to gain a deeper understanding of the meaning of community living from the perspective of select ageing and disability actors with relevant expertise. These interviews were also intended as a means of better appreciating both the synergies and barriers that exist with regard to alignment of approach between the disability and ageing sectors, both in principle and in practice. As well as the research question of how community living is conceptualised by stakeholders from the ageing and disability sectors, issues pertaining to their views on ageing and disability across the life course, the intersection of ageing and disability, the impact of disability on the experience of ageing and vice versa and more holistic policy frameworks were explored. In all, nine interviews were carried out between June 2017 and June 2018. Participants were policy and opinion leaders from the ageing and disability sectors at national and international level with expertise in policy-making, service provision and advocacy. Table 6.1 provides a breakdown of the stakeholder profiles.

Table 6.1 Stakeholder Profiles

Stakeholder	National/ International	Ageing Disability Ageing & Disability	Advocacy Policy Services
S/D/N1	National	Disability	Policy & Services
S/AD/N2	National	Ageing & Disability	Policy
S/AD/N3	National	Ageing & Disability	Advocacy & Policy
S/A/N4	National	Ageing	Policy Services
S/A/I1	International	Ageing	Advocacy & Policy
S/D/I2	International	Disability	Policy & Services
S/D/I3	International	Disability	Advocacy & Policy
S/A/I4	International	Ageing	Advocacy & Policy
S/AD/15	International	Ageing & Disability	Advocacy & Policy

Thematic analysis was the methodology employed for this phase of the empirical study. The six-stage approach as set out by Braun and Clarke (2006) was followed. On analysis of the data set, three themes with subthemes were discovered. Silos Rationalised included the subthemes of 'Holding Territory' and 'Reluctance to Associate'. Community Means Community contained the subthemes of 'Environment and Liveability' and 'Community Engagement'. Ageing and Disability as Processes subsumed the subthemes of 'Diversity' and 'Recognition'. The following sections will expand on these themes and subthemes. These themes are depicted in Figure 6.2. 'Phase Two Themes and Subthemes'.

Figure 6.2. Phase Two Themes and Subthemes



6.2 Silos Rationalised

The first theme, silos rationalised, derives from the reasoning that stakeholders applied to the separation and distinctions that exist in ageing and disability at individual, organisational and policy levels. Stakeholders acknowledged the benefits of greater cooperation between the sectors in areas such as community living. Indeed, community living was acknowledged as an area where there is much potential in terms of collaboration and cooperation. It was recognised that greater alignment of agendas and approaches could, potentially, deliver better outcomes for both sectors and particularly for people situated at the intersection of ageing and disability – i.e. older persons with disabilities. However, stakeholders also pointed to silo-specific stances as a barrier to community living, especially in issues such as continued adherence to age categorisation for services. They reflected on the need to move past such distinctions, given that goals are in actuality strikingly similar. Need rather than label or age was perceived to be the better barometer for supporting a person to continue to live well in the community. However, silos do continue to exist and two issues in particular were identified as serving to perpetuate them. These were reflected in the subthemes of 'holding territory' and 'reluctance to associate'. Development of these subthemes provided a means for understanding the continued existence of narrow silo-specific responses to policy issues such as community living.

6.2.1 Holding Territory

Symptomatic of the tensions that exist between the ageing and disability sectors, holding territory manifested in both attitude and approach and further perpetuated the existence of silos in policy and practice. Holding territory was recognised as manifesting in the monopolisation of issues and an unwillingness to concede ground. In respect of the monopolisation of issues, it was felt that both sectors have a tendency to pursue agendas that could be interpreted as favouring certain groups and, accordingly, could be construed as either 'disability issues' or 'ageing issues'. Examples of this are the promotion of employment in disability or home care in ageing as key areas of focus. Such prioritisation of disability or ageing issues as distinct rather than integrated life-course issues has an impact on the target representative groups. It can have an exclusionary effect for people who feel that their interests are not adequately addressed. Older people may feel that the agenda pursued by disability organisations does not sufficiently encompass ageing issues or the realities of older age.

Conversely, ageing agendas can sometimes be framed in terms that exclude people who have a life-course history of disability. This has consequences for representation in both sectors, but especially for people who are experiencing older age with the added dimension of disability. For this group, the distinction between ageing and disability is naturally blurred and it can be difficult for individuals to identify wholly as either an older person or a person with a disability, although this is often what is implicitly called for in order to be represented by either sector given the monopolisation of issues that occurs. An international stakeholder from the disability sector commented on this monopoly by stating that ageing organisations can sometimes *"claim older people to themselves as if nobody else gets old."* This comment was telling as it highlighted the holding of ground and the tensions that can follow. However, the same stakeholder was self-reflective and acknowledged that perhaps the disability sector has not done enough to make issues, such as independent living, relevant to older persons:

> *"We haven't done enough work I think on emphasising that it also includes older people. So I think we need to be more vocal in that respect, so yeah absolutely because it is such an artificial kind of division…I think we need to do a little bit more on promoting some examples of community-based services for older people with disabilities. We haven't done that and perhaps especially focussing on people who acquire their disability after the age of 65…"* (S/D/I3).

This acknowledgement highlighted that holding territory through the monopolisation of issues was not a one-sided issue, but rather spanned both sectors. It was apparent that stakeholders from both sectors were critical of the delineations that existed: *"You have disability-specific organisations and age-specific organisations and they don't necessarily align and intersect in their policies and practice in the way that you would expect, given the lived experience in relation to intersections"* (S/A/I4). Inherent in this criticism was an acknowledgement of the diversity of both disability and older age and the intersectional characteristics of older persons with disabilities that transcended into issues of common purpose.

Expanding on monopolisation of issues highlighted that holding territory was also closely linked to resource issues. Resource allocation was highlighted as a key source of tension between the ageing and disability sectors. An international stakeholder in the disability sector highlighted that this was a common issue across countries, despite the fact that support needs were strikingly similar in many cases: *"We see a sort of tension between the disability sector and the ageing sector because across Europe we see that authorities invest more in persons with disabilities and their services compared to the elderly"* (S/D/I2). Similar sentiments were expressed by a national stakeholder from the ageing sector, who, while offering a justification on the basis of stage of life, still highlighted the inequity and tensions that exist:

> *"You know the disability world is stronger at making the case about inequity but actually if you turn this around, there is an inequity to the older person because they might be lucky to get 5 or 10 or 6 or 7 hours of home help and that's fine because you are an older person but if you were 40 years or 30 years or 20, it's not so fine because you want different things and that wouldn't be enough at all"* (S/A/N4)

Stakeholders reasoned that the desire not to concede ground to the 'other side' could stem from a reluctance to enlarge the pool of support/service recipients from a resource perspective: *"I think what is an issue is you do get resistance from disabled people in different countries in terms of enlarging the pool of people who have access to personal assistance and it's because of limited resources"* (S/D/I3). Indeed, given austerity measures and the squeezing of budgets for all sectors, there existed a genuine fear of losing valuable and scarce resources for the particular group that each sector recognised as their primary focus. It was also felt that holding territory was necessary in order to maintain the gains that had already been hard won, with an international ageing stakeholder reflecting that perhaps this was strategic: *"A degree of being strategic and also maybe not wanting to lose ground with the perception that older people might be satisfied with less than with what more militant younger people with disabilities have been"*

(S/A/I4). Undoubtedly, a perceived and indeed often real inequity in the services and supports given to both sectors furthers tensions between the sectors. This served to rationalise continued adherence in many jurisdictions to cut-off age limits for services, such as the age of 65 years. An international ageing stakeholder felt that such age categorisations were legitimised by the disability sector to the detriment of older persons:

> *"It would break or remove from younger persons with disabilities many of the supports they are getting. That is why they insist to be speaking about persons with disabilities and older people as a separate group because it would be very very difficult and that's the main reason why those age limits have been introduced…you will have much more personal assistance type support if you are below 65 than if you are above 65"* (S/A/I1).

This view was supported by an international disability stakeholder, highlighting cross-sectorial awareness of a complicated and delicate issue, whereby resources need to be balanced but competing interests prevail: *"I think that in countries where older people don't have access to personal assistance, I would see also disability organisations being against opening it up to older people. They would probably argue that, which is the way the system is set up in many countries, that you would have to acquire your disability before the age of 65. It should be open to everyone"* (S/D/I3). It was also felt that such a stance was symptomatic of ageist and discriminatory attitudes within organisations as well as wider society: *"As I said this is part of the attitude that when you retire you are no longer worth it for the community. So you will get your basic needs, very basic needs like healthcare and support for showers and meals but for the rest you are on your own"* (S/A/I1).

The issue of discrimination was reiterated throughout the interviews in various forms, but often it related to the issue of resources: *"I don't think all of this is on the age advocacy community side because I think there is a holding of territory on the disability community side as well and probably a desire not to* *have the issue of disability flooded with older people and I wonder, there is probably an element I think, a strand of ageism in that"* (S/A/I4). However, notably, stakeholders, national and international, were united in their criticism of age categorisations and their role in perpetuating an ageing/disability divide. Although it was apparent that this was not to take from diversity of experience, as stakeholders were cognisant of the fluctuating dimension of need as a continuing factor in service provision:

> *"Obviously there will be emphasis for different people for their different needs if you are looking at need but absolutely a common approach to this and not having to jump bars because you are moving into a different category because you are now 65 or 66 or 80 or whatever"* (S/A/N2).

An Irish stakeholder in the disability policy and services field observed that it should not matter in reality if a person's services came from a disability programme or an older persons' programme, as it is all social care and, indeed, the difference was somewhat illusionary: *"What's important is to forget the label and the age. Say what is it you need right now and what are the challenges that you are facing in your life"* (S/D/N1). This stakeholder further opined that moving away from such strict categorisations for services would allow greater focus on a more person-centred approach to individual support needs: *"Always back to support. Instead of saying no it's not possible, say what would it take to do that. Ask a different question, what supports would need to be in place in order for him to continue living in his house"* (S/D/N1).

The reluctance to concede ground was evidenced at all levels, with an international disability stakeholder highlighting the reluctance at higher governmental level to share responsibility if it also meant losing resources: *"The real bottle-neck here is, and I'm doing political lobby work for 25 years now and I've never met a minister in 25 years who has been willing to hand over part of his budget to another ministry"* (S/D/I2). This was supported by Irish stakeholders, critical of governmental divisions which failed to recognise the intersectionality of issues: *“I have never come across any country that is more territorial than we are, I mean it’s circle the wagons”* (S/AD/N2). It was felt that these divisions were repeated down the level from policy to practice and reflected the divisions in society between different groups: *“I think one of the problems is government departments. They operate in silos and the thing that we have done in the community we have also done to government departments.”* (S/D/N1).

In attempting to rationalise why there existed such reluctance to concede ground, stakeholders opined that it sometimes comes from a place of fear, be it fear of change or fear of the unknown. From a service provision perspective, it could be a case of maintaining the status quo and doing things the way they had always been done. It was felt that sometimes service recipients themselves are unconsciously complicit in this as they tend not to complain owing to fears that they will lose what supports they have, even if supports in their current form were not what they wanted or needed. An Irish policy stakeholder termed this as such: *“People are so terrified of losing the little they have that they are afraid to talk about their likes. And yet we expect, we hope that we will move to a point where we will be blind to the disability but not blind to the needs and yet we don’t do it”* (S/AD/N2). In interpreting this, it appeared that while there was an appetite to move past age and label as measures of need, in reality people were still allocated services and supports along these lines and the hesitation to look at need more holistically was not delivering the best outcome for the person. For older persons with disabilities, whose service provision might be more precarious given their transcendence of sectors, this could be a significant factor in their continued life in the community, where supports are an essential component of community living.

To summarise the subtheme of holding territory, it manifested in acknowledged tensions between the sectors in both attitude and approach. Stakeholders recognised that both sectors can seem to cater to a primary category of persons in their agendas, which further perpetuates the existence of ‘disability issues’ and ‘ageing issues’. Tensions concerning limited resources and a fear of enlarging the pool of potential recipients were also identified as factors in perpetuating the silos in ageing and disability. In turn, this rationalised adherence to separate and distinct budgets and categorisations for services and supports.

6.2.2 Reluctance to Associate

Stakeholders also sought to rationalise the existence of ageing/disability silos by highlighting a reluctance to associate. Ageing and disability sectors can operate to an apparent mutual exclusion on multiple levels, including organisational, individual and policy. At policy level, the reluctance to collaborate, cooperate and coordinate within government departments was highlighted. Indeed, the reluctance to work together was identified by national and international stakeholders alike as existing at governmental departmental level: “We have huge issues in that we work in silos all the time” (S/AD/N3). From an organisational perspective, reluctance to associate can manifest in hesitation to work together on issues, even those of common interest and purpose. As a result, ageing and disability organisations will likely identify their membership base quite narrowly. This has particularly negative connotations for older persons with disabilities, who can be set apart from both sectors. An international disability stakeholder acknowledged failings in this regard: *“I think the disability organisations they don’t really bring together older people. It’s mostly people still active, still working so I think they are also excluding older people”* (S/D/I3). This reflects the tendency for disability organisations to focus their attention on people who have early onset or life-long disabilities, or in other words a life course history of disability.

However, it was acknowledged that there is a growing awareness of issues of intersectionality and the need to broaden bases in order to adequately meet the needs of growing diverse population groups such as older persons with disabilities. It was acknowledged that there were significant synergies and much potential in terms of sharing knowledge, experience and expertise on issues of mutual concern such as community living:

> *"Sometimes you need to step outside your core area of focus and listen to the debate that's going on. I actually did end up going to a conference on older people and it was fascinating. Even something like housing and adapted housing, the use of technology, one of the things that is grossly underestimated is the use of technology to support people to live independently. The ageing community are on that way more than we are. They are doing smart housing and we could learn a lot from them. And equally I think they could learn a lot from the disability sector in terms of person centeredness, assessment of support needs, the focus on the individual"* (S/D/N1).

In reasoning the reluctance to associate at organisational level, stakeholders were referencing their own experiences of being so heavily involved in one sector that there was neither the time nor the energy to associate with the other sector: *"Because of that disconnect and actually because I'm a good example of this…all I ever went to was disability stuff because you are so busy trying and I can't have all the things I would like to get to in disability so something comes on my desk about older people, well that's not my gig" (S/D/N1).* This was a common assertion as it was felt that there was potential to work together if only there was time and space to do so: *"I think it is possible to align those paradigms and so on but it does take time and effort and we are all just whirling around so fast all the time, hard to do it, and it needs a bit of vision and openness to that"* (S/A/I4).

The reluctance to associate at organisational level can have a consequential impact at individual level. It can lead older people to become reluctant to embrace the label of disabled, as it does not seem to fit their experiences. Equally, ageing organisations can frame their membership to the exclusion of people who have a life-course history of disability. An example is 'active retirement' groups, which are not always inclusive of those for whom employment and retirement have not featured as life stages. The notion of identity is strongly felt within this subtheme, as highlighted by an international disability stakeholder from the policy and advocacy field: *"I think if there was more older people were more* *involved they would feel happier to embrace the term disabled people. But it's true; I think it's kind of natural that people don't want to identify as disabled. I mean they are already getting old"* (S/D/I3).

This was interesting as the negative connotations that attach to both the label of older and disabled were alluded to throughout the interviews and for older persons with disabilities, this could be even more profound: *"Multiple discrimination on the ground of age and disability but really on the ground of age, you are being treated differently and you are not given the same rights…and then of course the support at home is different to what you get when you are younger"* (S/A/I1). For an older person, especially ageing into disability, the reluctance to associate with the disability dimension of their life was rationalised by stakeholders as being a natural human response and even a coping mechanism for their new reality of impairment. An international disability stakeholder put it in such terms that: *"It is clear that for ageing citizens it is not so easy for them to see themselves or to be labelled as disabled. They are senior citizens and that is already enough I think for them"* (S/D/I2).

In summarising reluctance to associate, it was clear that this was a cross-sectorial and multi-level issue. It was sometimes borne of factors beyond the control of organisations or individuals, such as time and resource issues. However, it was also intrinsically linked to self-identification. At organisational level, there is a core group for whom the organisation seeks to represent, be it older people or persons with disabilities. While there is a growing awareness of the need to reflect the interest of increasingly diverse population groups, this primary identification is still the case for the most part. At individual level, there is a reluctance to embrace multiple levels of identity and so older persons with disabilities are most likely to either identify as an older person or a person with a disability. This is linked to life-course factors, such as timing of disability onset, association with disability or ageing services, as well as issues of discrimination where embracing multiple labels is linked to multiple discrimination.

6.3 Community Means Community

The primacy of community was identified as a theme that was particularly relevant to the research question of how community living is conceptualised. Stakeholders spoke of the importance of actually being in the community to the experience of community living. This was broader than simply having a community presence as it extended to community integration and interaction. This was particularly relevant for older persons with disabilities who might find their ability to remain and interact in the community curtailed by both environmental and social factors. In this context, two subthemes were identified: environment and liveability and community engagement.

6.3.1 Environment and Liveability

Stakeholders universally highlighted the importance of older people with disabilities having the opportunity to live and age in the community. This hinged on having the requisite supports and services available and in place. The home environment was particularly relevant in this context as the home was acknowledged as being a significant factor in the person's independence and life satisfaction:

> *"The liveability of the home is very important. The environment matters as well as the social supports and the income as regards what you can do to live at home. People live in their home and communities that are extremely frail and disabled if they have that"* (S/AD/I4).

Stakeholders identified the need for the home environment to evolve and adapt to the changing needs of the person. This was particularly relevant in the context of persons ageing into disability and requiring home adaptations in order to help manage the new realities of their impairment. It was further felt that such adaptations could go a long way towards facilitating continuing independence and postposing entry into residential care. Supporting community living was, therefore, strongly linked to ensuring that the home environment was adequate to the needs of the older person with disabilities and would be a safe and comfortable environment for them to remain. However, it was acknowledged that planning has been lacking in this regard, with one national stakeholder commenting: *"We don't plan or think in advance…and we have known for some time of the living longer of older people and yet one of the big issues if people want to stay at home is the bathroom upstairs or the flexibility of the house to live in or to add on"* (S/AD/N3). This highlighted the practical issues for supporting community living that must be addressed. The ability to negotiate steps in the home and otherwise carry out activities of daily living were fundamentally linked to continued community living. This highlights that what is required is not always costly or complicated in terms of care and supports, but rather a re-evaluation of what is already in place and what can be adapted to meet changing needs in a responsive manner. It was evident that having suitable accommodation for older persons with disabilities was fundamental to community living and planning for this was a growing priority issue:

> *"We also started quite intensive cooperation with the housing sector, more specifically the social housing sector because providing or supporting people to live in the community requires the availability of accessible housing and of course an accessible environment so that the built environment is indeed also very important"* (S/D/I2).

Beyond the immediacy of the home, environment was highlighted as extending to ensuring that alternative options exist for the older person with a disability to remain in the community. It was felt that there needed to be options along a continuum from home to residential, with the latter being the last and final resort. Changing needs and new realities were acknowledged as significant factors in an older person with disabilities' ability to maintain a life in the community. However, it was felt that being in the community was of such fundamental importance that alternative avenues needed to be available in order to maintain the individual in the community for as long as possible. This would sometimes involve a negotiation and a balancing of need, rights and practicality. Although the home might become unsustainable, it was incumbent on policy makers to ensure that there were other community-based alternatives in place that responded to changing levels of dependency and support needs. A national policy stakeholder voiced this in such terms that there should be multiple options in order to stymy the numbers currently entering residential care unnecessarily but in the absence of viable alternatives:

> *"So they may have needs that are such that it becomes very difficult or almost impossible to have them live in their own home, despite what services they might get but they may not be of a level of dependency that requires, shall we call it traditional nursing home support, and I suppose because people really in general do not want to go to nursing homes or residential centres unless they really have to. We don't have a very strong third level or third order of sheltered accommodation/good supported accommodation that people could move to, or that would be available for them if they were in that half way house of not being able to live at home but not necessarily requiring long stay care"* (S/A/N4).

This viewpoint was reiterated and the absence of viable alternatives in the community was highlighted at the national level as being contrary to the idea of choice and supporting independence and autonomy in the community:

> *"To me, it means living where I want to be and making my choice. That may require some planning. At the moment I would say the options in Ireland are extremely limited. We don't have things like assisted living. We have small satellite places around the country but generally we don't. We haven't planned for living in the community if we need assistance at all"* (S/AD/N3).

As the numbers of older people continue to rise, there will naturally be a rise in the numbers of older persons with disabilities. Ensuring that homes and communities are suitable places for them to continue to live is therefore a priority issue and one which involves addressing practical issues such as how homes and communities can be adapted in order to meet changing needs along a continuum so that residential care is not a default option when people reach new fault lines in their own personal circumstances. This will be a constant reassessment and renegotiation but is important if older persons with disabilities are to be supported to truly remain a part of their communities for as long as possible.

6.3.2 Community Engagement

Encouraging and facilitating community engagement and participation was seen as central to community living. Having social networks and connections in the community was deemed integral to overall wellbeing and necessary to mitigate isolation and loneliness. Part of the notion of community engagement was harnessing the goodwill that exists in communities in order to make them more welcoming and inclusive places in which to live and age. Stakeholders highlighted that there is an inherent goodness in communities that can be harnessed in order to help people to remain part of their communities for longer.

Within this subtheme of community engagement was encapsulated elements of age-friendly communities. Ensuring that communities are welcome and inclusive environments in which to live and age were identified as being essential to the realisation of meaningful community living for older persons with disabilities. This extended to tacking issues such as discrimination and ageism and creating communities where older people felt supported and included. It was deemed essential that older people, irrespective of levels of impairment and consequential disability, are able to remain a part of their community and engaged in meaningful ways. This was felt to be an issue for all of society to address and an international ageing stakeholder highlighted that it involved attitudinal change:

> *"You need a welcoming atmosphere, you need to change the mentality, so some cities have started with that and it means training and encouraging*

> *shopkeepers and public transport staff but also a whole kind of activities around the public events, and so that will enable older people to feel safe and encourage them to get out, creating opportunities to mix generations. We don't want ghettos for older people. We want them to really be part of the communities…"* (S/A/I1)

Inherent in such an attitudinal shift was ensuring that older persons with disabilities were not merely seen as "care recipients" for whom once medication and basic needs were administered it was a case of "back in your sofa and that's it" (S/A/I1). Satisfying basic needs did not address the more fundamental need to feel connected, engaged and valued:

> *"Connection, meaning and purpose are for me absolutely core and whatever infrastructure you create around that to support and enable. So yes you need access to healthcare and support but if it's someone coming in for 10 minutes with plastic gloves to make sure you take your medicine, does that fulfil your need for connection, purpose and meaning? No! I rest my case!"* (S/A/I4)

Adopting such a narrow approach to addressing the needs of older persons with disabilities does not combat loneliness and social isolation. Loneliness was identified as an issue of grave and growing concern: *"The human being is meant to live in the community and not to live isolated and isolation is really the number one concern for older people. And you don't need to have a functional limitation or a disability to feel isolated but at least if you have no physical barrier you can try and do something…"* (S/A/I1). For older people experiencing the added dimension of disability, and perhaps confined to the one environment, isolation and loneliness could be more of a risk. Given that support networks can fluctuate, especially in older age, it is important that innovative practices are considered in order to maximise exposure to community and mitigate the effects of social isolation and loneliness. In some respects, this calls for a reimaging of community and harnessing the goodwill that currently exists in communities. Stakeholders referenced the need to draw on this in order to respond to the social needs of older people with disabilities and highlighted that it did not necessarily mean investment of large sums of money but rather innovation and planning: *"Encouraging the natural community supports so that people help each other…work on this community spirit, community cohesion etc…"* (S/D/I3). It was also felt that there is a need to move away from charitable models of support that perpetuate a passive image of age and disability. Pursuing more innovative models of support could have the dual effect of combatting negative stereotypes while promoting community engagement. Examples of this were moving away from the traditional 'meals on wheels' to more social excursions into the community:

> *"Also I would say meals on wheels is a very old fashioned paternalistic way of dealing with things. I see in West Cork the older person being brought into the local restaurant…have the drivers bring the people into the local restaurants and fund the food that way. Very much being part of the community…and that is what wellbeing is all about"* (S/AD/N3).

Community engagement was clearly identified as being essential to community living. Having a connection, feeling included and feeling part of something outside of oneself is part of the human condition. Older age and disability need not be barriers to community engagement, although they can sometimes decrease the opportunity for community engagement. However, as identified though the stakeholder interviews, it is evident that community engagement can be better achieved with innovative thinking and through utilising the social resources that already exist within communities.

6.4 Ageing and Disability as Processes

A third theme that was identified was that of ageing and disability being processes. The essence of this theme was the recognition by stakeholders that neither ageing nor disability is a static process but rather is dynamic. Accordingly, policy responses to the needs of older persons with disabilities need to reflect this. Ageing and disability do not exist independently of other factors. Personal circumstances as well as wider societal factors have a bearing in how ageing and disability are experienced. The subthemes of diversity and recognition fell under this theme.

6.4.1 Diversity

Stakeholders highlighted that as older people and persons with disabilities are not homogenous groups, it therefore follows that older persons with disabilities are also not a homogenous group. They are made up of people from diverse backgrounds with diverse life course histories and experiences. Appreciating the diversity of groups in society was deemed important in terms of recognising multifaceted dimensions to identity. An example of this was the welcome change in how older age is viewed: *"We finally hear that older people are a diverse group. Now that's a basic statement but my goodness, compared to the grey mass as perceived before, it's progress and you can build so much into that"* (S/A/I4). This signified that older age is now increasingly recognised as a time of continued potential and is experienced differently for individuals depending on myriad factors. A particularly significant factor in this diversity is timing of disability onset. Stakeholders differentiated between people who were ageing with disabilities and people who were ageing into disability. They felt that this distinction played a significant role in the experience of disability in older age. It was one of the more significant factors to consider when viewing ageing and disability as processes.

> *"It takes people a long time to identify as disabled even when they are younger but there is that time to get involved with some organisations or support groups etc. It's a process. I think that's why it is more difficult when people are older as well, people are more isolated anyway as they get older so they wouldn't come so much in touch with all the different support groups"* (S/D/I3).

Timing of disability onset has an impact in terms of supports that are required and supports that are available. People who have a life-course history of disability are not only more likely to identify as a person with a disability, but are also more likely to be imbedded in the apparatus of disability social care. This is significant for them in older age, as these supports are more likely to continue to be addressed under this umbrella as opposed to older persons services. This can be significant in terms of the range of supports that are available. However, it is also more likely that the person ageing with disability will have been precluded by health, opportunity or other circumstances from many of the established institutions of the life course, such as employment, independent living and long-term personal relationships/marriage. The lack of opportunity in these areas can have a consequential disadvantage that follows the person into older age.

An international disability stakeholder also highlighted that ageing with disability can sometimes be more profoundly felt: *"…even if they have a disability from early on, they generally do need more support as they get old. I mean even if their disability is not kind of classed as progressive, it is in a way progressive as their bodies age like everyone else's. So they do need more support as they grow older…"*(S/D/I3). Conversely, older persons ageing into disability will be more likely to identify with the ageing aspect of their identity and will experience disability in older age with a different arsenal of resources at their disposal. This may include the emotional and practical support of spouses and children, additional financial resources stemming from employment history, such as pension benefits and, quite significantly in many cases, a physical home of their own. Having access to these resources naturally affects the experience of disability and ageing and highlights how they are processes impacted by such factors.

Recognition of diversity is important in terms of not labelling people or trying to pigeonhole them into categories that are dictated by policy. The need to move beyond this was recognised, as were the barriers to so doing: *"Diversity and individualisation, these are the two concepts that we have to push in the future. But* *we should not forget that the entire legal and bureaucratic system is based on other concepts. Look at individuals and their wishes and desires"* (S/D/I2). Essentially, the need to move towards more individual responses to the needs of diverse groups in society was emphasised. This incorporated the need to bear in mind the life-course factors that impact on the lived experience of ageing and disability as dynamic processes.

6.4.2 Recognition

Inherent in the subtheme of recognition was the need to be cognisant of changing needs that accompany both the processes of ageing and disability. Both ageing and disability will affect people's lives in different ways and their needs will change along a continuum. It was highlighted that people themselves are not always capable or prepared to recognise the processes at work in their own lives:

> *"I think there may be a tendency to think of different experiences in old age as being part of the natural ageing process rather than actually identifying something as a disability…there is a huge issue in terms of recognition and that would be on the part of older people themselves because of how they expect ageing or expect to experience it as well as people around them"* (S/A/I4).

In unpacking what was meant by this theme, it would appear that recognising how ageing and disability are viewed objectively by wider society and subjectively by individuals necessitates addressing preconceived notions about what it means to age and what it means to experience disability. In so doing, it may be possible to better evaluate what responses are required in order to afford individuals the opportunity to live and age on their own terms, whatever that may be. There is a need to promote people's worth and ensure that they feel valued and supported. An international ageing/disability stakeholder enunciated this concept of worth as transcending labels: *"They don't want to be seen as a disabled person or a frail older person. They want to be valued and have more reciprocity with other* *members of their community"* (S/AD/I5). Part of this recognition of worth is respecting the wants and choices of older persons with disabilities, where choices are dictated in part by their changing circumstances. There is also a need to understand the part that ageist attitudes or discriminatory practices or exclusionary models of ageing play in perpetuating the exclusion of older persons with disabilities and limiting the choices available to them. The unfair assumptions that are made about older people with disabilities in respect of what they are willing to accept were highlighted. This was particularly relevant in the context of support where it is often assumed that family will step in and older persons with disabilities will accept this. However, it is important to bear in mind that such care relationships are rarely straightforward and can create imbalances:

> *"They definitely don't want to be a burden to their family members, that's a big thing especially for older people but for younger people too. They want independence as much as possible. They want to see their family members but they don't want to be dependent on them as much as possible"* (S/AD/I5).

Inherent in perception and recognition of worth was the understanding of individuals as having rights and needs that must be addressed without recourse to notions of contribution. In this context, ageing models based on notions of contribution and linked to productivity were especially criticised. Ageing and disability are processes that will be negotiated differently for different people with no definitive measure of 'success'. This is particularly important for older persons with disabilities who are experiencing all the nuances of ageing with the added dimension of disability:

> *"So it's about ageing on your own terms as a person in all its diversity and in a holistic way. There isn't a right or a wrong and all those models have something to offer us but they are only models. That's all they are. I just think we have to be very mindful of that. I think the other thing, just linking to the successful ageing, certainly that's not a disability-friendly model"* (S/A/I4).

The subjective nature of experience was highlighted, as was the need to appreciate the feelings of older people with disabilities, especially in later life often marked by more losses than gains, particularly in personal relationships: *"It is difficult to judge the quality of life. I think what really matters for people is whether somebody cares about you, the fact that you are there means something for someone else"* (S/I/I1).

Overall, the central premise of the theme of ageing and disability as processes, as expanded through the subthemes of diversity and recognition, was that ageing and disability are both dynamic processes influenced by factors within society and at a more fundamental individual level. Societal attitudes and policy responses as well as life-course factors impact on the experience of ageing and disability. Accordingly, there is not a one-size-fits-all response to the needs of groups such as older persons with disabilities. Responses must both respect and recognise the diversity of such population groups and seek to address their needs in a manner mindful of this diversity of experience and situation.

6.5 Chapter Summary

The aim of the stakeholder interviews was to gain a deeper understanding of how community living is viewed by people who are engaged in policy, services and advocacy in both the ageing and disability sectors. Semi-structured interviews were carried out with nine national and international stakeholders. Thematic analysis of the dataset led to the identification of three themes with associated subthemes.

The theme of silos rationalised included the subthemes of 'holding territory' and 'reluctance to associate', which together offered a better understanding of the continuing silo-specific nature of ageing and disability from both a policy and a practical standpoint. Indeed, despite increasing efforts to 'bridge' the two sectors, there remain barriers linked to issues of resources and identity among others. The theme of 'community means community' with the subthemes of ‘environment and liveability’ and ‘community engagement’ highlighted the centrality of community for both sectors in addressing community living issues. The theme of ‘ageing and disability as processes’ with the subthemes of ‘diversity’ and ‘recognition’ were valuable for the insight they gave into both the diversity within the older persons with disabilities demographic and the acknowledgement of this diversity that exists. There was also recognition of the need to be mindful of the voice of older persons with disabilities in policies that are designed and implemented to serve them.

Expanding on these themes highlighted nuances in understanding and interpretation of issues and both the potential and barriers to greater alignment within the sectors in policy areas such as community living. Overall, there was a common understanding of community living as a concept and a broad consensus on its constituent elements, being independent living, ageing in place and community engagement. However, it was also widely acknowledged that despite commonality of interest and purpose, there is some divergence with regard to the issues that are prioritised within both sectors. Furthermore, there is a certain tendency to monopolise issues or otherwise claim them as ‘ageing’ or ‘disability’ issues.

This chapter, together with the preceding chapter, has presented the data from the empirical work completed as part of this research study. Having set out and explored the findings, the next chapter will attempt to draw the threads together in a discussion and link the findings to the research questions.

Chapter Seven
Discussion and Conclusion

7.1 Introduction

This chapter seeks to relate the findings that have emerged from the research study to the guiding research question of how community living is conceptualised and experienced for older persons with disabilities. Consideration will be given to the extent to which the findings have illuminated the research question (Bryman, 2016) and added to the overall understanding of community living at the ageing/disability nexus. This chapter also endeavours to position the findings within the context of existing literature and policy, as explored in Chapters Two and Three respectively. Finally, the chapter offers reflections on the key contributions of the research study, including potential directions for future research, and draws some overall conclusions.

This research focused on the social policy of community living for older persons ageing with, and ageing into, disability. It was guided by the overarching research question of how is community living conceptualised and experienced by this heterogeneous group occupying space within both ageing and disability populations. Ancillary issues pertained to the influence of life-course factors on the experience of community living as well the factors contributing to the perpetuation of silos and the potential benefit of closer collaboration within the ageing and disability sectors. In light of the research question and mindful of these ancillary issues, I decided upon an empirical study adopting a qualitative design with a two-phase interview approach, aimed at capturing voice from older persons with disabilities themselves and insight from expert stakeholders in the aging and disability sectors.

The aim of the research study was not to establish objective facts, but rather to elicit a deeper understanding of community living for this group of people. Inclusion of the voice of older persons with disabilities was, therefore, an integral part of the research study and a guiding principle from the outset. Articulation of lived experience promised the most authentic account of what it meant to be an older person with a disability maintaining a life in the community. I sought to understand subjective experiences related to challenges and opportunities associated with community living. A constructivist grounded theory approach, guided by the work of (Charmaz, 2014) was compatible with the exploratory nature of this research study. This approach also sat well with my epistemological and ontological perspectives.

Phase One comprised twenty interviews with older persons with disabilities living in the community. This group were comprised of people ageing with disability and ageing into disability. The data collection strategy of purposive theoretical sampling was employed and following the tenets of the constructivist grounded theory approach, further participants were sought in order to address gaps and test the emergent findings until data saturation was reached. The participants had a range of physical, sensory, cognitive and intellectual disabilities, some lifelong and some acquired in mid and later life. They lived in both urban and rural areas, alone or with others. They had varying educational and socio-economic backgrounds. This mix reflected the diversity of the ageing population itself as well as adding to the richness of the data ultimately collected.

It became apparent through the interview process that the participants possessed varied and diverse life-course trajectories. This in turn contributed to the experience of community living in later life. Timing of disability onset dictated the nature and significance of a series of life-course factors within the study, including different life-course trajectories, different experiences of health and independence and different exposure to policy frameworks, with consequential implications for preferences and expectations. Echoing the experiences of Foley *et al.* (2014) in their grounded research study on ALS, utilisation of a life-course perspective was beneficial, particularly in contextualising, analysing and ultimately making sense of participants' subjective experiences of the subject matter.

Phase Two contextualised the lived experience of older persons with disabilities within the broader policy and operational landscape of ageing and disability. The objective of these interviews was not to delve deeply into specific jurisdictions or country-specific policies. Rather it was to capture a sense of community living as understood and promoted within both sectors. Furthermore, exploring silos and synergies operating within these sectors would add another layer of understanding to this policy issue. Participants with significant expertise in policymaking, service provision and advocacy were included in the study. National stakeholders could speak to particular community living dimensions in the Irish context, particularly issues such as the growing awareness of diversity within the ageing population and the evolving policy landscape of long-term supports. European stakeholders, cognisant of ageing and disability policies and trends, added insight to what is a complex and multifaceted social issue. International stakeholders added a broader perspective, offering examples of innovation that they had come across in the course of their own work. Given the multiplicity of stakeholders included in the study, a thematic analysis approach to semi-structured interviews was utilised in order to identify key themes from the research findings.

Stemming from this, the study had three objectives - to understand the constituent elements of community living, appreciate what community living means to older persons with disabilities and explore the perception of community living in the ageing and disability sectors. These objectives have been achieved not least owing to the rich and layered narratives that have been captured in the study. In many ways, the findings from both phases of the empirical study were complementary and informed an understanding of the ageing/disability nexus and the conceptualisation of community living for this population group and the ways that community living is related to life-course factors. The following sections discuss these particularly significant elements of the findings and link them to the research question as well as the literature explored in Chapter Two. Firstly, findings related to the disability nexus will be contextualised in relation to international literature. This will be followed by the conceptualisation of community living focusing on the centrality of community, considering both physical and intangible dimensions. Finally, the relationship between community living and life-course factors is discussed.

7.2 The Ageing/Disability Nexus

In this research, the ageing/disability nexus was a key focus area. Research has shown that there has been limited 'bridging' of ageing and disability in research, policy and practice (Putnam, 2014). However, there have been increasing calls for change on the basis of commonality of purpose, and a desire to achieve similar outcomes (Coyle and Mutchler, 2017, Nalder *et al.*, 2017) and address similar challenges such as exclusion and discrimination (Glasby, 2017). In policy areas such as community living this commonality is ever more apparent (Henning-Smith, 2017). A highlighted strength in bridging efforts has been the interdisciplinary nature of gerontology and disability studies (Coyle and Mutchler, 2017). Recognition of shared concerns together with an ageing population has added impetus to bridging efforts in ageing and disability (Leonardi, 2012, McDaid *et al.*, 2009).

In this study, and reflecting international literature (Craftman *et al.*, 2018, Henning-Smith, 2017, Löfqvist *et al.*, 2013), older persons with disabilities overwhelmingly expressed a desire to live independent lives in community settings with the supports and services necessary to help them realise this goal. However, in Ireland, as in many other countries, ageing and disability are treated apart as distinct entities with their own policies, operational plans and budgets (Leahy, 2018). This is significant for the population that straddles both sectors as they are both older and disabled and have intersectional characteristics (Heller, 2019; Bickenback *et al.*, 2012). These issues, which have been addressed more comprehensively in Chapters Two and Three, and which manifested in the findings of this study, have led to the perpetuation of silos that permeate both ageing and disability from research through to policy and practice. In these findings, as established in section 6.2, ageing and disability labels appear to be significant in re-enforcing the ageing/disability nexus and this provides insight into whether being older or disabled matters in the context of community living.

7.2.1 Older or Disabled and Does it Matter?

There is a lack of research on the particular experiences of people who occupy space at the ageing/disability nexus (Coyle and Mutchler, 2017), and less still concerning the particular issue of community living for this group. Research has tended to focus on the experiences of subgroups within the older disabled population, such as persons ageing with lifelong disabilities or intellectual disabilities (see for instance research of Bigby, 2002, Heller *et al.*, 2014, Heller *et al.*, 2015, Kåhlin *et al.*, 2015b, McCarron *et al.*, 2017). This research, while valuable, does not address the situation of all within the older disabled population who may be said to possess a hybrid identity. This research sought to address this gap by including the perspectives of people with early/lifelong, midlife and late onset disability.

Adoption of such a broad interpretation of older persons with disabilities was envisaged to capture diversity of experience and deliver a more comprehensive conceptualisation of community living. Individuals within the older disabled population may be categorised as older, disabled, or both, with such identification often hinging on arbitrary criteria, such as timing of disability onset or indeed the individual's own subjective sense of identity (Darling and Heckert, 2010; Kelley-Moore *et al.*, 2006). In this study, the extent to which participants emphasised one particular aspect of their identity over the other was largely linked to the timing of disability onset. Participants who had lifelong disabilities expressed a stronger disability identity and a closer affiliation with disability organisations, having carried the disability 'label' and interacted with disability services throughout their lives. Arguably, ascribing to ageing as another label was unnecessary as their identity and supports were already strongly influenced under disability. Furthermore, they were demonstrably more aware of rights issues and familiar with the language of advocacy. This aspect of identity affiliation aligned with previous research (Darling and Heckert, 2010).

However, this study also revealed that even though people who had aged into disability may not necessarily identify as disabled, there was an openness and familiarisation amongst these participants regarding issues of rights and supports that might be under the 'disability' umbrella. I would theorise that membership of support organisations and access to information are contributing factors in this regard. This correlates with previous research (Baxter et al, 2011) regarding the use of information in choice making by persons with disabilities, including older people. The work of Baxter and colleagues showed that information is central to informed decision-making and highlighted that in some cases people who have not had experience with disability services, owing to a gradual onset of support needs, may be disadvantaged in the information stakes, despite having other resources such as education and social capacity. This is an important consideration for people ageing into disability.

It was evident that participants who experienced disability for the first time in older age were more likely to view their disability as a secondary aspect of their identity. For this group, disability added another dimension to the ageing experience. Some participants were slow to even acknowledge their experience as that of disability. This reluctance would suggest that stigma or medicalisation of disability (Naue and Kroll, 2010) were concerns and conscious considerations in not identifying with disability. In particular, hearing and mobility impairments, which impacted on the ability to function and interact in the community, were frequently underplayed as the price of growing older (Grenier *et al.*, 2016). Undoubtedly, participants demonstrated resilience in 'getting on' with this perceived aspect of ageing. This under-emphasis on disability was perhaps also owing to having had other aspects of identity dominate for the greater part of their lives and having fulfilled more societally recognised roles (Kelley-Moore *et al.*, 2006). This is in keeping with the research of Darling and Heckert (2010) in respect of orientation of ageing or disability identity being linked to timing of disability onset.

Capturing broad perspectives in this study was also intended to deliver a better assessment of the extent to which life-course factors impacted on the conceptualisation and lived experience of community living. Appreciating the significance of life-course factors is important in the context of understanding the meaningful elements of community living. Despite the identity rootedness of participants either ageing with, or ageing into, disability, their views on the meaning of community living and the most valuable elements were quite consistent. They expressed similar desires to lead independent lives and maintain personal connections in the community (Löfqvist *et al.*, 2013; Dale *et al.*, 2012). Participants with a life-course history of institutionalised living and participants who had always lived independently equally valued these elements of independence and inclusion.

Overall, and reflecting previous research (Neville *et al.*, 2018), participants both ageing with and into disability were shown to esteem friendships for their practical and emotional support and were keen to maintain their social networks. These social networks are central to support and connection in the community. These social support networks were experienced and maintained through participation and social interactions in the community (Golden *et al.*, 2009). While deep and meaningful friendships were valued by many of the participants, more fleeting encounters were also appreciated. These included casual interactions while going about the business of daily life in the community or greetings shared with faces from the past. This reflects the findings of May and Muir's study (2015) that such encounters could be important for an older person's sense of belonging in a place. This is significant as it suggests that community living can be augmented through informal networks as well as those more established.

Relationships with family and professional supporters were also viewed in similar terms by those ageing with and ageing into disability, with the desire for support balanced with the desire for autonomy. Participants also expressed similar concerns about their ability to maintain their independence in the future, which supports the findings of previous research (Lindquist *et al.*, 2016). In striving to maintain independence, participants ageing with and ageing into disability encountered similar challenges in terms of accessing appropriate services and supports. Therefore while self-identification made participants more likely to access services through ageing or disability avenues, ultimately their values and views on the practicalities of community living were strikingly similar. Essentially, all participants were cognisant about what they needed to live, and age, well in their communities; however, it was in accessing these services and supports that divergence was seen.

It is noteworthy that participants with lifelong disabilities were more accepting and comfortable with formal support. Echoing Swedish research (Kåhlin *et al.*, 2015b), it may be theorised that this was owing to experience of interacting with services throughout their lives. Nevertheless, reflecting the familiarity with supports that this study revealed, the findings also demonstrated that there was openness amongst people ageing into disability to the possibility of formal supports as a means to maintaining independence in the community, albeit a supported or negotiated independence. In this way control and autonomy is retained over the services required to facilitate continued independence (Haak *et al.*, 2007). Choice and control as opposed to self-sufficiency are the key to independence in this context (Rabiee, 2013).

Stakeholder findings revealed that the measure of a good life was intrinsically linked to feeling wanted, needed and included. One ageing stakeholder summarised the measure of a life in terms of losses and gains with the ultimate goal of meaning something to someone else. This supports the supposition that all people are interdependent (Glasby, 2017) in society and need exists along a continuum (O'Shea *et al.*, 2017). This also reflects notions of interdependence where older persons with disabilities could also be fulfilling caring roles (Di Gessa and Grundy, 2017; Berridge, 2012). This challenges the notion that there is a 'proper' way to age well or successfully, instead recognising the complexity of human diversity and experiences of older age (Van Dyk *et al.*, 2013, Gunnarsson, 2009). Viewing ageing and disability narrowly does not do justice to this interdependence (Holstein and Minkler, 2003). Adopting a more holistic view emphasises the richness of human diversity and experience in view of the totality of life's triumphs and challenges contextualised by societal factors (Gibney *et al.*, 2019, Park, 2011) and demonstrates that small measures in recognition of this complexity can make significant and positive impacts in peoples lives (Clarke and Warren, 2007). Furthermore, these findings add credence to the assertion that greater alignment between the ageing and disability sectors could potentially deliver better outcomes for groups with intersectional characteristics (Coyle and Mutchler, 2017, Monahan and Wolf, 2014).

Stakeholders offered further insight regarding this issue of orientation within ageing and disability. Ageing and disability as distinct labels each carry their own connotations, which more often than not are discriminatory and based on negative stereotypes and out-dated notions of what it means to be older or disabled, being inherently ageist or ablest (Larsson and Jönson, 2018). Biggs and Daatland (2004) reflected that despite the growing diversity of the older population, stereotypes persist. It was therefore understandable that a number of stakeholders opined that perhaps one label was enough for older people coming to experience disability in later life. However, for people with a life-course history of disability, there was a greater connection to that aspect of their identity. The stakeholder findings also revealed an acknowledgement of the heterogeneity of the older disabled population group and that the standard labels heretofore utilised may no longer apply. These findings corroborate those of the community interviews where older persons with disabilities were shown to be complex and more than the sum of any one aspect of their identity.

7.2.2 Silos and Synergies

Ageing and disability for the most part operate along lines of demarcation, which trickle down into policies, practices and attitudes. Difference is rooted in research and policy agendas formulated on separate frameworks and models of ageing and disability (Nalder *et al.*, 2017, Monahan and Wolf, 2014). Organisations primarily orientate themselves in ageing or disability, targeting and attracting their members on this basis. Governmental departments and social care services have separate remits, responsibilities and budgets. This leads to the perpetuation of silos, which divide ageing and disability from policy through to practice (Putnam, 2014). In discussing silos, Putnam (2014) points to their roots in chronological age categorisations for services and disability-specific focus (i.e. intellectual disability services etc.) Furthermore, Putnam (2014) has highlighted a historical motivation to disentangle stereotypes in both sectors. This study aligns with this view as stakeholders alluded to such motivations articulated through the finding 'silos rationalised' and the subtheme 'reluctance to associate'.

Stakeholders offered considerable insight on barriers to integration and coordination within the respective sectors that echoed previous research on the existence of silos (Heller, 2019, Heller *et al.*, 2014, Putnam, 2014). There was a common acknowledgement that the continued existence of such silos are detrimental to the needs of both older persons and persons with disabilities. Rationalising the perpetuation of silos on territorial grounds was linked to issues of resources, responsibility and agendas. They also pointed to barriers to association including scarcity of time resources. That the findings revealed recognition of these silos was construed as positive as acknowledgment is a necessary step to overcoming them. This is important for more inclusive and holistic policy responses given that "neither people's lives nor policies exist in sectorial silos" (Gayle-Geddes, 2016, p.xiv).

Putnam (2014), while acknowledging the challenges in overcoming silos through bridging efforts, also highlighted the new ‘ideological convergences’ that disability and ageing are discovering through their common interest in community living. In a similar vein, and in the context of discussing the need to integrate both sectors, Coyle and Mutchler (2017) point to ancillary issues such as age-friendly communities as being a good point for both sectors to develop a common approach. The research findings presented here support such a contention. Stakeholders acknowledged that community living, and associated elements, such as age-friendly and accessible communities, were areas of policy where commonality could be found and enhanced. Knowledge transfers and cooperation could deliver better outcomes for both sectors in promoting community living. Measures such as the provision of accessible services accommodate and benefit different groups in the community in a holistic manner linking age-friendly and disability-friendly communities (Yeh *et al.*, 2016; Lowen *et al.,* 2015).

That the findings revealed potential of greater alignment of agendas and approaches may also be construed as positive and significant. The findings highlighted that attitudes and mentalities within both sectors are changing and becoming more cognisant of the evolving nature of ageing and disability as concepts and more importantly as lived experiences. Recognition of the diversity at the ageing/disability nexus and the potential benefits of designing policy responses along more holistic lines is a positive step, which demonstrates an appetite and a willingness to change. This study therefore aligns with previous calls (Nalder *et al.*, 2017) for support to be based on need irrespective of age or disability categorisations. In capturing a broad diversity of life-course experiences amongst older persons with disabilities, this study highlights the commonality in community living that rationalises such an approach.

These findings support the design of policy responses along more fluid lines rather than the basis of narrow distinctions or age and condition categorisations. This study also adds support to the assertion of Monahan and Wolf (2014) that focusing more on convergence than divisions would better capture the essential issues faced by the older disabled population as a whole. The stakeholder findings emphasised that ageing and disability are evolving concepts and new understandings about abilities and rights have called for a reimagining of what it means to be older, disabled or indeed both. This supports the need for greater exploration of diversity within both population groups to ensure that the needs of groups with intersectional characteristics are addressed (Nesbitt and Johnson, 2019).

However, this potential for more holistic policy responses is not advocated with a disregard for the risks associated with the dissolution of silos. A tension must be acknowledged whereby in combining policy, a doubling up of the social constructions of stigma and dependence could result. Caution is therefore necessary in how we think about combining these policy discourses. There is a need to ensure that any such responses are more holistic and reflective of both ageing and disability experiences, lest we run the risk of perpetuating further issues and disadvantage. There are critical issues at play and complex cases behind all of the arguments, and undoubtedly there is no easy fix. However, without at least advancing our understanding of the blurred nature of ageing and disability experiences, and sectors, the required progress for these groups will always be impeded.

7.3 Conceptualising Community Living

How older persons with disabilities conceptualise and experience community living was the overarching research question in this study. It motivated Phase One of the empirical study, wherein participants were asked to articulate what community living meant to them. From this starting point, accounts were expanded upon that described various elements of life in the community for these participants. These narratives generated the five themes that are explored in depth in Chapter 5. The stakeholders in their interpretation of meaningful community living substantiated many of the views voiced by older persons with disabilities. The following subsections will consider two important aspects of community living as conceptualised in this study – the centrality of community and the community environment.

7.3.1 The Centrality of Community

A unifying thread throughout the narratives was the importance of physical embeddedness in the community itself for both the realisation and maintenance of meaningful community living. This was reiterated by ageing and disability stakeholders who spoke of the importance of actually being in the community as both an older person and a person with a disability. This study demonstrated that community served an important role in the lives of older persons with disabilities. Being in the community was the gateway to independence, autonomy and inclusion – essential expressions of meaningful community living. Furthermore, being in the community offered advantages over institutionalised living arrangements and promoted overall wellbeing.

Independence and autonomy

Perhaps unsurprisingly, participants regardless of age or disability status overwhelmingly valued living in the community over alternative options. They enjoyed living in their own homes, irrespective of form, as even participants who lived in community group homes could contrast this with institutionalised living and point to the very real differences that community living offered. The main difference manifested in the sense of control that having one's own domain offered. Participants who lived alone or with spouses echoed this as having one's own home allowed them to retain their independence in a real sense. This study's findings aligned with evidence of Stones and Gullifer (2016) that showed autonomy manifested in control over daily life. Participants in their study felt that home afforded maximum autonomy and independence and ensured that they were "beholden to no one" and could live the way they chose. Across the sample, irrespective of timing of disability onset, this study showed that older persons with disabilities place an extremely high value on their independence and autonomy. In a similar vein, this study aligns with research in environmental gerontology that links the home with independence and autonomy (Wiles *et al.*, 2011, Spoorenberg *et al.*, 2015) whose participants linked remaining in their own homes with independence and autonomy. This locates this research within the wider body of work on environmental gerontology (see for instance Rowles and Bernard, 2013b).

In this study, the link between home and independence was clearly demonstrated by participants such as Frank, who felt that by living in his own home in the community he could "do absolutely anything you like." Furthermore, Frank highlighted that living independently in the community allowed people to get on better and do more for themselves. This undeniably fostered Frank's feelings of confidence and self-worth. This aligns with research of Haak *et al.* (2007) pertaining to the significance of home for independence and autonomy and of Black *et al.* (2015) on the importance of self-reliance related to ageing in place. This study demonstrated that these notions of independence were strong throughout the sample of diverse ages, disability types and life-course experiences, demonstrating that the home could be a place of continuing independence for older persons with disabilities (Cagney *et al.*, 2013). With the right supports and interventions, the home could continue to be a place of autonomy, affording older persons with disabilities the tools to maintain their independence and identity (Van Hoof *et al.*, 2010).

Community living afforded a satisfactory degree of independence and autonomy for most participants. Participants valued their established routines and this continuity was linked to overall feelings of contentment. These routines could be as simple as shopping or going to the local hairdressers. However, their importance was much deeper as these acts were assertions of independence and allowed participants to navigate life in the community on their own terms. This was not to say that supports were not acknowledged and accepted and in many cases both formal and informal support facilitated the maintenance of such independence. This study reflected findings from research of Grimmer *et al.*

(2015) on ageing in place in Australia who also showed that older persons with disabilities are aware of the requisite supports to facilitate continued independence. Furthermore, this study aligns with the supposition of Grimmer and colleagues (2015) that interventions aimed at supporting community living need not be costly but rather should be flexible and tailored in order to promote ageing in place. Participants in this study were acutely aware of what they needed to maintain their lives in the community and in the majority of cases they were not costly interventions but simple measures such as assistive technology (Owuor *et al.*, 2017) ground floor accommodation, minor home adaptations or physical therapies to maintain independence (Van Hoof *et al.*, 2010, Lien *et al.*, 2015, Smith *et al.*, 2008).

In the more social sense, they desired interactions with others for a sense of companionship and a sense of purpose. In these cases, substantial financial resources were not required but rather joined-up thinking and a harnessing of existing good will in the community. Research has highlighted the importance of social embeddedness as well as congruence with the environment (Mejía *et al.*, 2017). Research (Lien *et al.*, 2015) has also shown that older persons with disabilities engage in behaviours to maintain a person-environment fit including adjusting attitudes/behaviours, increasing environmental supports and counteracting functional losses. Such adaptive strategies were also to the forefront of the minds of participants in this study.

This research study highlighted that older persons with disabilities are aware of their fluctuating needs and changing circumstances. Participants recognised that their lives in the community were not guaranteed and that as their needs progressed, they would likely become susceptible to external variables such as the availability of services and supports. This was a source of unease for some participants who felt that they were not getting supports adequate to meet their needs and this threatened their independence in the community. The future was less assured for these participants and they worried about the time when they may be forced out of necessity to enter into residential care. Participants expressed concerns about deterioration of their conditions and the loss of independence and voiced worries about ageing (Cooper and Bigby, 2014). However, the study also showed that older persons with disabilities are adept in managing their conditions and new realities and demonstrate a willingness to compromise in order to remain in the community. They are prepared to accept a certain encroachment on their independence and indeed this was expected in some cases. This compromised independence was deemed acceptable as it avoided unwelcome alternatives such as being reliant on family members or entering into residential care (Wiles *et al.*, 2011).

Findings from the stakeholder interviews corroborated the view that community living could be sustained despite fluctuating needs. Viewing community living along a continuum with a reassessment of services and supports in line with changing needs would facilitate prolonged independence in the community. In this way, a gradual move away from full independence towards residential care would be the preferred route. There was a belief among some stakeholders that the current continuum is too balanced towards residential care and that with more innovation residential care could be avoided for longer. This belief is reflected in research and policy (Boutaugh and Lawrence, 2015, Wren *et al.*, 2012, Nursing Home Support Scheme). Despite requiring varying levels of support, participants all experienced meaningful community in their own way. Even amongst participants who objectively might seem to have limited community interactions or receive significant supports, contentment with their version of community living was demonstrated. This highlighted the value of even negotiated independence where it facilitated the living of life on one's own terms. It also adds credence to an assertion from the research of Minkler *et al.* (2008) that living in the community was not about being "functionally perfect" (p.118) as such a view is inherently negative, disempowering and flawed.

Avoiding institutional living was a strong motivation for participants to maintain their lives in their community. In all respects, participants believed that they were better off living and ageing in the community. They felt that in the community they could retain a significant degree of choice and control that would be lost were they to enter into a nursing home. This aligns with research on environments of ageing (Löfqvist *et al.*, 2013, Spoorenberg *et al.*, 2015). This is corroborated by evidence demonstrating that loss in domains such as independence and autonomy may be experienced in residential care (Lee *et al.*, 2016). Being in the community also afforded persons ageing with disabilities the opportunities to engage in activities that are not always facilitated or permitted in institutionalised living arrangements. Participants who had transitioned out of residential units to homes in the community were able to engage in new activities such as cooking and shopping and manage homes of their own. They articulated that their competence and confidence in these activities had increased and that overall they were living and ageing well in the community despite experiencing disabilities. This reflects research of King and colleagues (2017) who found that older persons with disabilities were more active in ADLs and IADLs in the community than in residential settings.

Social Interaction

The centrality of community was borne out in the opportunities for social engagement that it afforded. This research revealed social interaction to be one of the essential components of community living for older persons with disabilities. Depending on individual circumstances, participants in this study were able to maintain their relationships with family and friends and in all cases; being in their own homes and communities enhanced these opportunities. Furthermore, that participants in this study felt supported by their families to age in place and maintain their independence was a reflection of findings in the study of Stones and Gullifer (2016) on older adult's perceptions of ageing in place. Participants were also able to maintain ties with former work colleagues and in so doing retain important aspects of their identity which had been developed over the course of their life. They were able to participate in community initiatives such as active retirement groups and attend social clubs in their locality. These were also shown to be invaluable sources of support. Furthermore, aligning with the findings of Wiles *et al.* (2011), such social interactions in the community allowed participants to feel attached to their community as "insiders"**.** As with other research (Even-Zohar, 2014), this research highlighted that social connections were strong motivators for wanting to remain living in communities, despite changing circumstances and new realities.

The centrality of community as a key to social interaction was also emphasised from the stakeholder perspective. The assertion that community could be fostered and augmented was a particularly interesting aspect of this perspective. Stakeholders highlighted that maintaining a person in the community was not always about financial resources but also down to innovative thinking and a harnessing of social resources, emphasising the importance of community interactions and social supports. Again this aligns with the assertion of Grimmer and colleagues (2015) that interventions to promote ageing in place need not necessarily be costly.

7.3.2 Environment and Community Living

Community had a special meaning for all the participants in the study. This was community interpreted in the broadest sense of environment, attachments and relationships (Verbrugge, 2016). This was the encapsulation of what community itself means to people. Environment encompassed home and neighbourhood as well as wider amenities and social outlets. Relationships were broadly construed as being both close and casual in form. Environment and relationships were closely intertwined in the community for the participants. Their interactions within the community, both at micro and macro level, altered in line with changing circumstances. This sometimes necessitated negotiation, modification or compromise in order to maintain and sustain community living. Significantly, the findings revealed that depth of attachment and contentment within the environment was not always determined by length of time.

Home Environment

This research study supports the prominent position that the home occupies in later life as evidenced in ageing in place literature (Wahl *et al.*, 2009). Cagney *et al.* (2013) describe the home as a place of familiarity and comfort that may also facilitate continued independence. This is possible where there is a P-E fit that matches the functional needs of the individual with the home environment. In this research study, many participants had come to experience disability in older age and this necessitated modifying their home environment in order to achieve this match. For some, this involved assistive devices in the home such as handrails or accessible bathrooms and for others it meant accepting formal and informal help with ADLs. Accordingly, this study has demonstrated that a good P-E match is possible in older age even where the added dimension of disability is considered. In instances where competences and environmental press are balanced, the home can continue to be a place of independence and autonomy for older persons with disabilities. In this respect, this research study substantiates that of Lien *et al.* (2015) who elaborated on the adaptive environmental strategies such as home modifications employed by functionally limited community-dwelling older people in order to achieve P-E fit.

Although this study demonstrated that a P-E fit was achievable, particularly in the context of persons ageing into disability, it also highlighted that older persons with disabilities are cognisant that their experience of disability could impact on their ability to maintain independence. They were aware that adequate services and supports might not be available to them, further impacting on their ability to sustain their community living. This corroborates the findings from the study of Lindquist *et al.* (2016), which highlighted the precarity of older persons regarding advanced life events that may threaten their ability to remain independent and age in place.

Some participants had lived in the same home for most of their adult lives and, perhaps unsurprisingly, demonstrated strong feelings of attachment. In such cases, the home was embedded with memories of family and significant moments and milestones. The home could be construed as a “warehouse of memories connecting the past and present self” (Stones and Gullifer, 2016). Living in their own homes, participants could expect visits from family, friends and neighbours and this was a valuable source of both physical and emotional support and afforded a sense of belonging. In this respect, this research aligns with that of Stones and Gullifer (2016), who found that the home was not only a seat of independence and autonomy but also a conduit for social connections and intrinsically linked to identity. In the home, participants could continue their roles as parent, grandparent and continue to derive a sense of self-worth. In essence, being in their homes anchored participants to their past and their community. This reflected the sense that the home is a place of belonging, in “our experience, recollection, imagination, and aspirations” (Chaudhury and Rowles, 2005)

However, as previously noted, this study also demonstrated that depth of attachment is not necessarily time contingent. Some participants, including returning emigrants and former institutional residents, had moved to their homes and communities later in life and yet still demonstrated similar feelings of attachment and contentment. For all participants, it could be said that these feelings were intrinsically linked to belonging and agency. Wahl and Oswald (2010) discuss these constructs in the context of the P-E interchange in later life. It was evident that the participants in this study had engaged in compensatory and adaptive behaviours in order to remain in their homes such was the depth of attachment to the home. An example of this was Sadie, who found ingenious ways of adapting the home to her physical limitations. This aligns with the previous research related to independence in the home and findings that highlighted adaptive actions (Haak *et al.*, 2007).

Community Environment

The environment of the wider community was also demonstrated to be of significance in the lives of older persons with disabilities. This supports the view of Oswald *et al.* (2010) that wellbeing in later life is linked to environmental resources. The majority of participants in this study spoke of the community resources, such as transport services, health facilities and social clubs, as being central to their ability to remain living in their own homes and communities. These resources were demonstrated to be particularly significant in light of new realities of impairment and disability. A number of participants who had come to experience sensory and mobility impairments in older age were no longer vehicular mobile. While this was acknowledged to be a blow to independence, the participants were keen to highlight that the effects were mitigated by a reliable and convenient bus service in their locality. This parallels evidence from the study of Van Dijk *et al.* (2015) on the ideal neighbourhood for ageing in place for frail and non-frail community-dwelling individuals. It also reflects research (Mackenzie *et al.*, 2015), which linked positive home/community connections with the ability to remain at home despite disability onset. In this study, participants also valued a safe neighbourhood with facilities in close proximity that would facilitate them to continue to live independently in the community, linking with the view that community environments should be accessible, supportive and promote independence as people's needs change. Conversely, barriers in the community, both physical, institutional and attitudinal served as complicit factors in the exclusion process of older persons with disabilities.

This study also aligned with evidence of Singelenberg *et al.* (2014) that social interaction in the community contributes to overall wellbeing and a sense of meaningfulness that is important for older persons even when experiencing limitations. Participants in this study wanted to feel included in the community and valued the contributions they could still make. This was clear from participants such as Ronan who took pride in his singing for the enjoyment of others in his community and Dermot who valued his ability to contribute to educational and historical projects in his community. Furthermore, this research study echoed the aforementioned Dutch findings of Singelenberg *et al.* (2014) that even casual encounters in the community such as interactions in shops or cafes could be more valuable than formal social programmes. Such interactions or 'incidental encounters' can be significant to a person's sense of belonging in a place and contentment is not necessarily contingent on strong social ties where a general sense of comfort in the place exists (May and Muir, 2015). The findings of Singelenberg *et al.* (2014) demonstrated that formal interventions were not for everyone and for some older persons with disabilities informal encounters could be meaningful. In this study, this was demonstrably the case for Catherine, who felt uplifted by casual encounters with the friends of her children when they returned to the neighbourhood to visit. This speaks to the subjective appreciation of social interactions and the supposition that responses to individual needs should be tailored as there is no one-size-fits-all response. This is significant given the increasing focus on addressing the negative affects of loneliness as a policy priority (Holt-Lunstad, 2017, Gerst-Emerson and Jayawardhana, 2015).

7.4 Community Living and Life Course Factors

This study has explored community living from the perspective of older persons with disabilities, both ageing with and ageing into disability. This distinction related to timing of disability onset and has been explored in some detail in Chapter Two. As outlined earlier in this chapter, this distinction did not have a material effect on the conceptualisation of community living. For all participants, meaningful community living was linked to independence, support, home and environment and social interaction, with a common thread of resilience unifying their experiences. These elements were intrinsically linked in the lived experience of community living for this group. However, it was in exploring these elements in the context of the life course that the distinction of ‘ageing with’ and ‘ageing into’ disability became more apparent. Attainment of a broad view of community living as experienced in the older disabled population must take account of this distinction.

7.4.1 Achieving and Sustaining Community Living

The participants in this study made community living meaningful on their own terms, working with the resources and supports at their disposal. It was within the parameters of these available resources and supports that the influence of the life-course factors was most keenly felt. Manifested in the manner by which participants negotiated their lives in the community, the impact of timing of disability onset, and the other facets of life that this coloured, became most apparent. This aligns with Monahan and Wolf (2014) who highlighted the different perspectives that tend to be associated with ageing and disability depending on timing of disability onset. In considering this impact, I would like to focus particularly on independence, support and social interaction. It was in these domains that the impact and lasting effects of life-course variances were most pronounced. These domains were interconnected as for instance the impact of life-course factors on independence naturally impacted on support. The following sections will highlight some of these effects and contrasts within the older disabled population, as revealed by this study.

7.4.2 Domains and Life Course Variance

In capturing a broad diversity of experience, this study revealed variance of life-course trajectories, which impacted on the experience of community living in older age. In the domain of independence, a readily apparent contrast was the experience of participants engaging with disability for the first time in older age and participants with lifelong disabilities. Participants with intellectual disabilities in this study had all experienced institutionalised living. They had transitioned out of residential settings to homes in the community in later life. Reflecting the findings of Salmon *et al.* (2019), participants in this study expressed the choice to move to community as an expression of independence and autonomy. The move to community delivered many of the positive effects that were identified by Bredewold *et al.* (2018) in their systematic review of the impact of de-institutionalisation. These included improved quality of life and improved community living skills with more opportunities for social interaction and self-determination. Participants in this study articulated these positive effects of transitioning to community living in terms such as “freedom” and being “invested” in society/community. However, their life-course history of institutionalisation had a lasting effect. The absence of independence had permeated all facets of life, impacting on choices, opportunities and relationships. Participants alluded to this in the loss of opportunities, the lack of choice and freedoms that they had experienced across their individual life course. However, the participants in this study did not highlight the negative effects of de-institutionalisation that were identified by Bredewold *et al.* (2018), such as victimisation or increased reliance on family members. Arguably, the fact that the participants in this study were well supported by their social networks and service providers in their lives in the community had a bearing on their overall positive experiences.

A number of participants in this study had come to experience disability for the first time in middle age and, accordingly, could be categorised as ageing with disability. For these participants, the challenges typically associated with older age such as shrinking social networks, limited resources, threats to independence, were felt to varying degrees. However, they also were dealing with the progression of their conditions. For Catherine, this was further sensory deterioration that necessitated increasing support from family members. For Michelle, it was the progression of her condition that necessitated home adaptations. In both cases, additional measures and supports were accepted as means to maintain independence. Catherine and Michelle were keen to retain their respective social roles and avoid institutional care. They had developed ways of managing their conditions and maximising their independence. This echoes the findings of Cooper and Bigby (2014) in their study of adaptive strategies across the life course. In their study, participants were also adept at managing their conditions in older age and were similarly eager to maintain their independence and social roles. Furthermore, both the participants in this study ageing with disability and the participants in Cooper and Bigby's (2014) study were comfortable with the disability label and would be prepared to access services through this avenue. The participants in this study who were ageing with lifelong disabilities were determined not to be re-institutionalised. Institutionalised living arrangements, having been their reality for a significant portion of their lives, were not viewed as an inevitability and were simply too high a price to pay for growing older.

Within the domain of support, the experiences of participants ageing with and ageing into disability could also be contrasted. The majority of participants ageing with disabilities in this study had not married or had children. Furthermore, for some institutionalisation had impacted on their relationships with family members including siblings. This absence of familial support was apparent in their narratives surrounding community living in contrast to participants who had relationships with spouses, children and wider family members. Community living is very much linked to having informal supports and the absence of same is a barrier to the experience of meaningful community living.

Timing of disability onset also impacted social interactions. Participants who were ageing with disability had experienced less opportunities to engage with others either professionally in educational and work situations or more socially. This had impacted on their social networks in older age. Although living in the community, the difference in social networks was strikingly apparent. Even amongst participants ageing into disability who had not married or had children, there were robust social networks consisting of former work colleagues, friends from hobbies, neighbours and the like. Echoing findings from studies carried out in Sweden as part of a research project on disability, life course and ageing (Jeppsson Grassman *et al.*, 2012), this study found that identity and social interactions were shaped by earlier life-course experiences, particularly involvement with disability organisations. For these participants, earlier advocacy involvement continued to shape engagement in the community, and indeed expectations for what supports and services should be forthcoming to maintain their lives in the community.

Participants ageing with disabilities more readily identified as being disabled and were active in disability organisations or organisations related to their particular condition. This could be contrasted with participants who were ageing into disability, whose social interactions often stemmed from previous stages of their life course such as employment and volunteering. As well as attending active retirement groups, many of these participants regularly met with former colleagues and friends they had met through work and volunteering activities. Undoubtedly this contributed to their having a demonstrably larger social network that was to an extent independent of their ageing or disability status. This contrast therefore arguably owed to life-course variance.

This research study also corroborates findings from the study of Raymond and Grenier (2015) on social participation for older persons with disabilities and the manner by which older person's organisations and programmes can possibly exclude older persons with lifelong disabilities. This owes to attitudinal, environmental and organisational barriers. Again, this is can be seen in the way that organisations such as active retirement groups reflect a life-course trajectory that often excludes the perspective of persons ageing with disabilities. In this study, persons ageing with disabilities, particularly intellectual disabilities, did not take part in active retirement groups. The circles of support stemming from engagement within these networks were beyond the reach of the majority of the participants ageing with disabilities. Undoubtedly for participants in this study, this owed to an absence of the life-course experiences, which provided the 'in' to such forums, as well as attitudinal and other barriers. This study therefore echoes the call of Raymond and Grenier (2015) for ageing frameworks to be more attuned to diversity and support the participation of people who require additional supports and accommodations.

7.5 Reflections on the Research Study

The aim of the research study was to facilitate a better understanding of what community living means for older people with disabilities. This population group is becoming more diverse owing to both an ageing general population and increasing numbers of persons with disabilities living into older age (Heller, 2019). There is also a growing focus on rights for populations groups such as older people and persons with disabilities and associated changes in policy responses (Leonardi *et al.*, 2012, De Hert and Mantovani, 2011, Doron and Apter, 2010). In Ireland, this is evidenced though policy developments pertaining to deinstitutionalisation (Health Service Executive, 2011) personalisation (Fleming *et al.*, 2016) and home care (Kiersey and Coleman, 2017). All of these developments impact on the views, expectations and preferences of people for community living.

7.5.1 Limitations

All research studies have their strengths as well as their limitations. One limitation of this study was that it did not include the perspective of older persons with disabilities living in institutional settings such as residential homes or nursing homes. The rationale for this exclusion was presented in Chapter 4 and hinged on the view that people actually experiencing the realities and challenges of living in the community with a disability were best placed to offer the requisite insight on the topic. However, the exclusion of the perspective of older people living in institutions must be acknowledged as a potential limitation. Inclusion of the voice of persons denied, either though circumstances, resources, or policies, the opportunity to live in the community would have added further illumination to the conceptualisation of community living. This would have afforded an additional viewpoint through which to explore community living and the influence of life-course factors contributing to the experience of institutionalised living.

A further limitation is that 'hard to reach' participants may not have been sufficiently captured within this study. This may have included older persons with disabilities, who may not be active in their communities, may not be sufficiently supported and may not be managing as well in the community. These are the complex cases that holistic policy responses must also take account of and respond to. However, issues relating to accessing and recruiting participants have been discussed in Chapter 4 and this study was guided by the principles of qualitative research and constructivist grounded theory (Charmaz, 2012) and informed decisions relating to sample size saturation and completing analysis were made throughout the process of fieldwork and data analysis (Mason, 2010). Recruitment efforts were as comprehensive as possible given the time and resource constraints of a research study of this nature.

7.5.2 Future Research Directions

Older persons with disabilities are increasingly significant, both in number and as a group to be considered in ageing and disability policies. There is both scope and an imperative to delve deeper into older persons with disabilities as a group and focus on intersectional locations encompassing both diversity of people and diversity of place. This would include, although it is not limited to, gender, socio-economic circumstances, geographical location and living arrangements. For example, the role of place in the experience of community living could be explored. This would allow for consideration of both the essential elements and the experience of community living in light of an urban/rural divide. In the context of services, supports and social interactions that serve as facilitators to community living, this would be particularly interesting as it would expand upon the degree to which location influences experience and serves as either a facilitator or inhibitor to community living. As communities continue to experience change, not only in respect of demographics but also economic factors, the impact of this on the experience of community living would be a worthy exploration.

Dementia is attracting increasing attention as a priority focus area in both research and policy. It is an area where ageing and disability arguably intersect considerably. Exploring community living in the particular context of dementia would allow for an in-depth study of how conceptualisation aligns with experience. There is also potential in tracking people ageing with disabilities who have transitioned out of institutionalised living arrangements and who may be at risk of falling back into institutions in older age. The response to this group and the cyclical nature of living arrangements is worthy of further research, especially in the context of disability rights that rallies against institutionalisation.

This study has focused on the experience of community living for older persons with disabilities living in the community. An expansion of this would be to undertake a study capturing the perspective of persons who have aged into disability and are now experiencing institutionalised living arrangements. Such participants, having transitioned from community to more institutionalised living arrangements (e.g. nursing homes) could potentially offer a comparative view of their differing experiences. The extent to which the experience of disability was a precursor to this transition would offer insight into the essential elements of community living and how they could possibly be enhanced and facilitated to avoid institutional care.

7.6 Research Study Contributions

In light of the overarching aim of the research to conceptualise community living at the ageing/disability nexus and the key empirical findings outlined earlier in this chapter, this study makes a number of contributions. The most significant contributions relate to the areas of theory, method and policy.

7.6.1 Theoretical Contribution

Ageing/Disability Nexus

This study makes a theoretical contribution to the limited but expanding understanding of lived experience at the ageing/disability nexus and the impact of life-course factors on these experiences. This group comprises both people ageing with and ageing into disability. Specifically seeking to include the perspectives and experiences of participants with early, mid and late onset disability and furthermore diverse disability types allowed for a life-course dimension to be incorporated into the study. In applying a life-course perspective, the study took account of how timing of disability onset influenced the significance of a series of life-course factors, including different life-course trajectories, experiences of health and independence and exposure to policy frameworks, with the aforementioned consequential implications for preferences and expectations. The study has demonstrated that despite varying life-course trajectories, there is not a vast divergence between what persons ageing with and ageing into disability value. This contribution addresses the relative paucity of information concerning lived experience for this group and how it relates to policy agendas in both ageing and disability. Including a broad range of older persons with disabilities highlighted a shared set of experiences, which add to our overall understanding of the ageing/disability nexus.

Community Living

This study was foremost about community living and entailed asking older persons with disabilities to articulate what the idea of community living meant to them. Participants were invited to elaborate upon their accounts of life in the community so as to identify the elements of community living of most importance to them. This study therefore offers theoretical insights into what constitutes meaningful community living for this group that straddles sectors. The centrality of community, the importance of social interaction, the maintenance of independence and the value of support were all revealed to be important, irrespective of timing of disability onset. Community, in its broadest interpretation, was demonstrated to be of paramount importance in the lives of older persons with disabilities. The desire to maintain community living on ones own terms was also demonstrated through the findings. Community living was revealed to be a negotiation between need and acceptance with resilience playing a significant role in making the best of life in the community in older age with the added dimension of disability. Expanding on the contribution to understandings of the ageing/disability nexus, this study also demonstrated that although life-course factors had a bearing on resources in older age, their wants and desires relating to community living were not materially different. Across the sample, similar components of community living were identified as being essential to the experience of meaningful community living.

Bridging

The study also makes a theoretical contribution to bridging efforts in gerontology and disability studies. A growing body of research champions interdisciplinary efforts to bridge ageing and disability. This research adds its support to this effort and in so doing makes a valuable contribution to the bridging agenda. The study has demonstrated that there is much value in conducting research that captures the lived reality of life at the ageing/disability nexus in order to expand bridging efforts. Furthermore, the findings from the stakeholder interviews demonstrated that ageing and disability have many commonalities in the policy area of community living and that there exists significant potential for collaborative research endeavours to further explore and build upon these commonalities. There are risks associated with not moving past siloed responses. This study lends support to calls for greater collaborative measures and interdisciplinary efforts to address the needs of cross-sectorial groups in society. In a time of increasing focus on the value of interdisciplinary approaches, research that has adopted just such an approach is valuable.

7.6.2 Methodological Contribution

Recruiting a Diverse Sample

This study highlights that active, collaborative and sensitive engagement with stakeholders and gatekeepers can overcome obstacles in recruitment of a diverse sample. Accordingly, it makes a methodological contribution in this regard. This study was significant in that it sought to capture a diverse sample by including not only participants who have aged into disability, or in other terms acquired their disability in later life, but also people who are ageing with disability, either lifelong or acquired in early or midlife. Sample diversity, giving rise to rich data, was in part achieved though engaged collaboration with stakeholders and community groups. This allowed me to gain the confidence and support of these contacts in order to access participants, particularly participants with intellectual disabilities in supported group accommodations. These were participants whose voice is often excluded from research owing to difficulties in accessing and inclusion.

Constructivist Grounded Theory

This study makes a methodological contribution by highlighting how the voice of older persons with disabilities can be included in research. Conducting interviews with participants who had a range of conditions and sensory, physical, intellectual and cognitive impairments presented methodological challenges. It was necessary to design a research study that was ethically sound and also responsive to the particular needs of the participants. Cognisant of these challenges, an interview approach that was sensitive and attuned to the ethical considerations of conducting interviews with older persons with disabilities was designed.

In not adopting a narrow focus on particular disabilities, this study has brought the voice of intellectual disability to gerontology. It demonstrates how a constructivist grounded theory approach can be utilised when conducting research with older persons with disabilities, including intellectual disabilities. Furthermore, the use of life-course biographical interviews demonstrated the value of an inductive approach, which allowed for the articulation of voice.

7.6.3 Policy Contribution

Age and Disability are Subjective

The policy implications of this study are that it demonstrates that the subjective experience of community living transcends arbitrary policy divides rooted in age categorisations or labels. As highlighted in Chapter 3, there continues to be a demarcation in ageing and disability on which policy responses are predicated. In the context of older persons with disabilities, this has the effect of excluding the particular challenges and experiences associated with disability in the ageing policy debates and vice versa. That ageing and disability policies can be weak or silent on the other's interests increases the likelihood of this group falling through the cracks and not receiving the support required to live and age in their communities. This increases the risk of premature or unnecessary institutionalisation. This study highlighted some of the incongruences relating to the availability and provisions of supports depending on location within ageing or disability services. Given the common aspirations of older persons with disabilities, both those ageing with and those ageing into disability, to live and age well in their communities, such arbitrary distinctions are at worst inequitable and at best unfair.

Policies pertaining to community living either directly or indirectly are often designed from silo specific standpoint setting disability and age apart. However, this belies the life-course dimensions of both ageing and disability wherein existence is fluid, change is natural and adaptation is possible. The elements that are essential to community living are equally applicable to older people and persons with disabilities. Furthermore, it emphasises the need for policies to incorporate the totality of the ageing and disability experience. This means not construing either ageing or disability narrowly by focusing on one-dimensional concerns.

Community Living Viewed Along a Continuum

This study has revealed the multifaceted nature of community living for the older disabled population. While highlighting that life-course factors, such as timing of disability onset, may impact on the material and social resources necessary for the maintenance of meaningful community living, it has also demonstrated that wants are much the same. Persons ageing with and ageing into disability ultimately desire the same outcomes. This is to maintain independence and autonomy as much as possible and remain in their familiar and socially connected environments for as long as possible. Just as this study has provided a theoretical contribution to meaning, there is also a practical value in illustrating that for policy. The purposes of interactions remain the same despite different points of entry to disability. This means exploring alternative options along a continuum from full independence in the home to institutionalisation in nursing or residential homes. These are two bookends along a continuum that allows room for much innovation in terms of housing, services and supports. This means providing the formal supports that are necessary to facilitate community living. This means fortifying informal carers so that they can continue to provide invaluable support to family and friends seeking to maintain independence in the community. This means challenging ageist and ablest stereotypes that still prevail and recognising that there is no right or wrong way to live and age in the community and that lived experience is subjective. This means making our communities a supportive place in which to age with disability. Communities have the potential to be welcoming spaces for diverse groups in society (Rowles and Bernard, 2013a). Age-friendly communities are also disability-friendly communities and the overall goal of policy should be to promote accessible and inclusive communities that allow for meaningful community living across the life course.

Voice in Policy

Perhaps the most important contribution that this study makes to policy lies in the articulation of voice. This is powerful in that voice informs policy and also points to the potential for older persons with disabilities themselves to lead policy given that they are best placed to express their needs and wants. This study demonstrates that neither disability nor older age should be construed as a barrier to this recognition and appreciation of voice. In their responses to social issues, policy makers and stakeholders should strive to overcome ageist or ablest notions and ensure that the perspective of older persons with disabilities is incorporated into policies. So doing tempers the rhetoric of ageing populations and associated challenges with recognition of the heterogeneity of this population and the opportunity to design policies that will benefit the older population as a whole. A growing older population is naturally of relevance to social policies that concern older people and the quality of their lives (Walker and Maltby, 2012). A national conversation about age and disability has already begun and will continue to gain momentum. This study demonstrates the value of recognising the voice of older persons with disabilities in this conversation.

7.7 Conclusion

As the number of older persons with disabilities increases, adherence to narrow interpretations of ageing and disability will become less tenable. As evolving concepts, there is an increasing need for inclusion of diverse perspectives to better inform policy responses to cross-sectorial issues such as community living. Older persons with disabilities offer one such perspective. As a group, they encompass the life-course experiences of people ageing with and ageing into disability. These experiences, stemming from timing of disability onset, are intrinsically linked to the components of meaningful community living that were revealed through this study. Although the life-course trajectories of older persons with disabilities were shown to be different, their shared values relating to community living were the same. They desired independence, autonomy, familiarity and inclusion.

Designing community living policies that are reflective of the heterogeneity of older persons with disabilities has the potential to take account of life-course factors. These factors, operating across the life course, influence life-course trajectories and impact on the exercise and maintenance of community living in older age. This research study has offered an interpretation of community living that takes account of this variance and diversity of experience. Interpreting this policy area within the context of the life course has shown the benefit of pursuing more inclusive and holistic policies, which are reflective of both the ageing and disability experience, and which may ultimately lead to more meaningful and sustainable community living for older persons with disabilities.

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APPENDICES

Appendix A: Phase One Participant Profiles

Participant	Marital Status	Number of Children	Location/ Living Arrangement	Disability	Age
Catherine	Widowed	5	Urban City/Alone	Sensory	77
Veronica	Single	0	Urban City/Alone	Physical	74
Ronan	Married	0	Urban City/Spouse	Sensory/Cognitive	83
John	Married	1	Suburban/Spouse	Physical/Ssensory	81
Joanna	Married	4	Rural/Spouse	Physical	78
Sadie	Widowed	5	Urban City/ Alone	Physical	76
Eithne	Married	1	Rural/Spouse	Physical	93
Mark	Widowed	0	Urban City/ Alone	Physical	75
Dermot	Single	0	Urban City/ Alone	Physical/Sensory/ Psychosocial	81
Joseph	Married	3	Rural/Spouse	Physical/Cognitive	78
Michelle	Single	0	Urban Town/ Alone	Physical	57
David	Single	0	Suburban/Alone	Physical/ Intellectual	65
Finula	Single	0	Urban Town/Alone	Physical/Sensory	83
Brigit	Single	0	Suburban/Alone	Physical/Sensory	84
Liam	Single	0	Suburban/Alone	Intellectual	66
Fiona	Single	0	Urban City/Alone	Physical/ Intellectual	56
Joe	Widowed	3	Suburban Town/ Alone	Physical/Sensory	83
Matt	Widowed	6	Rural/Alone	Physical/Sensory	86
Shane	Single	0	Suburban Town/ Shared	Intellectual	51
Frank	Single	0	Suburban Town/ Shared	Intellectual	52

Appendix B: Participant Information Sheet – Phase One

PARTICIPANT INFORMATION SHEET

Exploring Community Living from a Life-course Perspective – Toward Life-course Policy Options

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My name is Emily Loughlin and I am a PhD student at NUI, Galway. My research involves exploring the meaning of community living for older people and persons with disabilities. The research aims to make policy recommendations for a life-course policy framework for community living. Such a policy framework would facilitate all people, irrespective of age or disability, to enhance their natural support networks and build an infrastructure of interdependence that would benefit them throughout the life course. A life-course policy framework would also be more adaptable and responsive to a person's changing needs and circumstances.

As part of my research, I would like to conduct interviews with up to twenty people aged over fifty who are living in the community and who have a physical or a cognitive disability. Each interview will last approximately one hour. If you would like to participate, I would like to hear about your experiences of community living and the relationships and supports that have helped you to live, and age, well in the community.

The information that you provide will be valuable to my research as it will give me a better insight into the real life experiences of people living with a disability in the community. The study's findings will help me to understand what community living actually means for older people and people with disabilities. This understanding will be beneficial to me in making a case for a non cohort-specific life-course policy framework for community living.

Findings from the interviews will be analysed and used to generate ideas about community living and the meanings of dependence, independence and interdependence. Based on the initial analysis, certain key themes may emerge. You may be invited to take part in a short follow-up interview to discuss some of these themes in greater detail. Participation in this study is completely voluntary. If you wish to withdraw from the interview, you can do so at any time without giving a reason or an explanation.

Interviews will be audio recorded and will then be typed up. The information you give me will be kept strictly confidential. Extracts from interviews may be used in publications or presentations as part of my research, but all names, personal details and any other identifying information will be removed or changed to protect the identity of those taking part. I will keep the recordings, transcripts and affiliated consent forms for five years past the end of the project in 2018 in conformity with international data protection standards.

If you have any further questions regarding the research or taking part please contact:
Emily Loughlin
Irish Centre for Social Gerontology, Institute for Lifecourse and Society,
NUI Galway.
Email: e.loughlin8@nuigalway.ie
Tel: 00 353 86 3768035

Appendix C: Accessible Information Sheet – Phase One

Accessible Information Sheet

My name is Emily and I am a PhD student at NUI Galway	NUI Galway OÉ Gaillimh 
I am researching what it means to live in the community for older people and people with disabilities.	
You can help me by talking with me for around 1 hour.	

I want to hear about how you live your life at home and what it means for you to live in the community.	 
I want to hear about the important people in your life that help and support you.	 

You will have the chance to tell me about your life in the community. Sometimes people get upset when they talk. If you get upset I can help you find someone to talk with.	
You can say that you don't want to answer any question. We can also stop the interview at any time and I won't mind.	
The interview will be recorded and then written up.	
Your name will not appear in anything I write or talk about.	

What you tell me will help me in my research. **I will write about what you say in my research and maybe give a talk about it. If you want I can invite you to come to the talk.**	 
The recording of our talk will be stored on Emily's computer in a protected file. **All the information you give me will be destroyed after 5 years.**	 
If you would like to take part in an interview, contact Emily: **Emily Loughlin,** **Centre for Disability Law and Policy, ILAS Building, NUI Galway.** **Phone: 086 3768035** **Email: e.loughlin8@nuigalway.ie**	✉ ☎ @ 📱

Appendix D: Participant Information Sheet – Phase Two

PARTICIPANT INFORMATION SHEET

Exploring Community Living from a Life-course Perspective –
Toward Life-course Policy Options

My name is Emily Loughlin and I am a PhD student at NUI, Galway. My research involves exploring the meaning of community living for older people and persons with disabilities. The aim of this research is to make policy recommendations for a life-course policy framework for community living. Such a policy framework would facilitate all people, irrespective of age or disability, to enhance their natural support networks and build an infrastructure of interdependence that would benefit them throughout the life course. A life-course policy framework would be more adaptable and responsive to a person's changing needs and circumstances.

As part of my research, I would like to conduct interviews with approximately ten national and international stakeholders, opinion and policy makers and leaders from the disability and ageing sectors. Each interview will last approximately one hour. I would like to hear about your perspective of community living and how you view its conceptualisation in the ageing and/or disability sector.

The information that you provide will be valuable to my research as it will give me a better insight into community living and the policy issues surrounding this concept. The findings from this study will help me to understand community living from the viewpoint of the people who are actively engaged in the ageing and disability sectors and who may represent the interests of members of both groups. Data from the interviews will be analysed and used to generate ideas about community living and the meaning of interdependence. These ideas and insights will be beneficial to me in making a case for a non cohort-specific life-course policy framework for community living.

Interviews will be recorded on an audio recording device and will then be typed up. The information you give me will be kept strictly confidential. Extracts from interviews may be used in publications or presentations, but all names, personal details and any other identifying information will be removed or changed to protect the identity of those taking part. I will keep the recordings, transcripts and affiliated consent forms for five years past the end of the project in 2018 in conformity with international data protection standards. Participation in this study is completely voluntary. If you wish to withdraw from the interview, you can do so at any time without giving a reason or an explanation.

If you have any further questions regarding the research or taking part please contact:
Emily Loughlin
Irish Centre for Social Gerontology, Institute for Lifecourse and Society,
NUI Galway.
Email: e.loughlin8@nuigalway.ie
Tel: 00 353 86 3768035

Appendix E: Consent Form – Phase One

Consent Form for Participants

Exploring Community Living from a Life-course Perspective – Toward Lifecourse Policy Options

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Thank you for participating in this research study exploring community living across the life course. I will conduct an interview with you and other participants about your experiences of, and perspective on community living. I will take notes during our conversation and audio record the discussion.

I will not share specific information that you provide with anyone who is not involved in this research project. However, the general findings from this study will form part of my research and I may share them in research presentations or publications. In such instances, it will not be possible to identify you from the material. During the discussion, feel free to decline to answer any questions and to end your participation in the research should you feel uncomfortable at any stage.

If you have questions or concerns about this consent form or about the research, please contact:

Emily Loughlin

Irish Centre for Social Gerontology

Institute for Lifecourse and Society,

NUI Galway.

Email: e.loughlin8@nuigalway.ie

By signing this form, I agree that:

- I have read and understood the copy of the information sheet on the research study that I have been given and any questions I have had have been satisfactorily answered.
- I have read this form and understand how I will be participating.
- My participation in this study is completely voluntary.
- I consent to being interviewed and audio recorded by the researcher.
- I understand that I may withdraw my participation from the study at any stage during the research, without giving a reason.
- I understand that my name and address and any other identifiable information will be kept confidential and that the information I provide will be treated with confidentiality and will be stored in a secure place.

Participant Name Printed: ____

Participant Signature: ____

Date: ____________________________

Researcher Name Printed: ____

Researcher Signature: ____

Date: ____________________________

Appendix F: Accessible Consent Form – Phase One

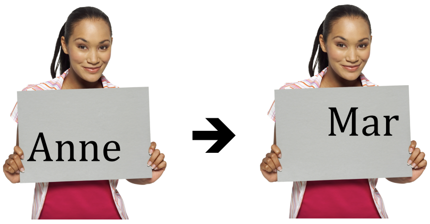
Accessible Consent Form

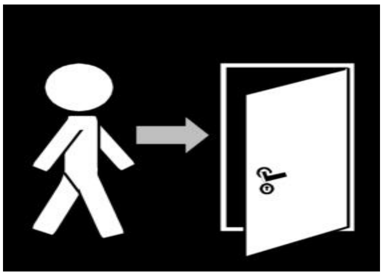
Exploring Community Living from a Lifecourse Perspective – Toward Lifecourse Policy Options

Consent form	

My name is……………………………..……..…..

	Please circle		
	I have enough information about the research.	✓ Yes	✗ No
	I was able to ask questions about the research.	✓ Yes	✗ No

	I understand that what I say will be recorded.	✓ Yes	✗ No
 	I am happy for the things I say to be used in the research. For writing a report and telling other people.	✓ Yes	✗ No
	I understand that my name will not be used.	✓ Yes	✗ No
	I understand that only people involved in this research study will know that I said what I said.	✓ Yes	✗ No
	I understand that Emily will have to tell someone if I or someone else is at risk of being hurt.	✓ Yes	✗ No

	I understand that I can leave anytime that I want.	✓ Yes	✗ No
	I understand that taking part just means having a chat with Emily, nothing more.	✓ Yes	✗ No
	**I agree to take part in the research.**	✓ Yes	✗ No

Signed……………………………………

Date………………………………………

Appendix G: Consent Form – Phase Two

Consent Form for Participants
Exploring Community Living from a Life-course Perspective – Toward Lifecourse Policy Options

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Thank you for participating in this research study exploring community living across the life course. I will conduct an interview with you and other participants about your experiences of, and perspective on community living. I will take notes during our conversation and audio record the discussion.

General findings from this study will form part of my research and I may share them in research presentations or publications. In such instances, all efforts will be made to ensure that it will not be possible to identify you from the material (unless you have consented otherwise). However, given the subject matter and the scale of the sector involved, this cannot be guaranteed. During the discussion, feel free to decline to answer any questions and to end your participation in the research should you feel uncomfortable at any stage.

If you have questions or concerns about this consent form or about the research, please contact:

Emily Loughlin

Irish Centre for Social Gerontology

Institute for Lifecourse and Society,

NUI Galway.

Email: e.loughlin8@nuigalway.ie

By signing this form, I agree that:

- I have read and understood the copy of the information sheet on the research study that I have been given and any questions I have had have been satisfactorily answered.
- I have read this form and understand how I will be participating.
- My participation in this study is completely voluntary.
- I consent to being interviewed and audio recorded by the researcher.
- I understand that I may withdraw my participation from the study at any stage during the research, without giving a reason.
- I understand that my name and any other identifiable information will be kept confidential (unless otherwise consented) and that the information I provide will be treated with confidentiality (as previously outlined) and will be stored in a secure place.

Participant Name Printed: ____

Participant Signature: ____

Date: ____________________

Researcher Name Printed: ______________________________________

Researcher Signature: ______________________________________

Date: ____________________

Appendix H: Research Protocol for Distressed Participants

Ethics Protocol for Distressed Participants

Exploring Community Living from a Life-course Perspective
– Towards Life-course Policy Options

In the event of distress arising during the course of interviews with participants, the following procedure will be adopted:

- The interview will be stopped, the audio recorder will be turned off and the participant will be asked if they would like to take a break.

- If the participant continues to be distressed, they will be asked if they would like to end the interview and either withdraw from the study or alternatively postpone the interview and reschedule for another time.

- The participant will be asked if there is anyone that they would like the researcher to call to support them (e.g. support worker, family member, counselling service).

The following are the contact details of national organisations and groups that can be provided to a distressed participant.

- Citizens Information 1890 777121
- National Advocacy Service for People with Disabilities 076 1073000
- Society of Saint Vincent de Paul 01 838 6990
- Irish Advocacy Network (peer advocacy for people with experience of mental health services) 047 38918
- Samaritans (Confidential Emotional Support) 1850 609090
- Aware (Mental Health Support) 1890 303302
- GROW (Mental Health Support) 1890 474474
- Senior Help Line (Confidential Listening Service for Older People) 1850 44 0444

Appendix I: Interview Guide – Phase One

Interview Guide for Participants - Phase I

- Narrative interviews
- Participants will be asked to share their experiences of community living

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General themes of the interviews:

- Community Living
- Independent Living
- Dependence, Independence and Interdependence
- Lifecourse
- Ageing in Place

Initial Question: Can you tell me about your experience of community living? Themes that may be explored in greater depth, initiated by prompt questions, only as required and as appropriate to the particular circumstances of the interview:

Community Living:

- Can you tell me about the people in your life that help and support you to remain living independently in the community?
- What kind of help and support do these people offer and provide?
- Are there ways in which you in turn offer support to the people in your life?
    - If so, is this relationship of interdependence important to you?
    - Do you think that this help and support may change in the future?
- Do you feel that community living has meant something different to you at different stages of your life?
- What do you think are the key factors for successful community living?
- Have you experienced any barriers that have hindered your ability to live independently in the community?

Policy:

- Do you feel that policies for community living should be more flexible and applicable to all people, regardless of age or disability?
- Do you think that such a life course policy for community living would better support you to remain living independently in the community as you age?
- Have you encountered any policy barriers that have made it more difficult for you to remain living independently in the community?
- From your experience, what supports for community living would you like to see contained in policy?

Appendix J: Accessible Interview Guide – Phase One

Interview Guide
Participants with Intellectual Disabilities

- Narrative interviews.
- Participants will be asked to share their experiences of community living.
- Initial open question followed by prompts as required.

General themes of the interviews:

Community Living
This encompasses elements including:

- Independent Living
- Dependence, Independence and Interdependence
- Social Inclusion
- The life course
- Ageing in Place

These elements may be explored by prompt questions under the headings of home, neighbourhood, activities and people.

Policy
The questions under this theme are intended to capture the participant's views relating to the important elements, as well as the barriers, associated with community living.

Initial Question: Tell me about your experience of community living?

Prompts may be used to explore general themes in greater detail and will only be used as required depending on the particular circumstances of each interview.

Community Living:

Home

- Can you tell me a bit about your home? (Probe in relation to description, rooms etc.)
- Have you lived in this home for long?
- Tell me about where you lived before.
- Do you live with other people now?
- What kind of jobs do you do around the house? (Probe in relation to household tasks such as cooking, cleaning, gardening etc.)
- Do people come to visit you at home? (Probe if appropriate re who, duration etc.)

Neighbourhood

- What are the best things about living in your neighbourhood? (Probe for location, neighbours, services etc.)
- How do you feel living in your neighbourhood?

- What are the best things about living in the community? (Probe for examples of choice and control, social inclusion, activities, amenities etc.)
- Is where you live now better than where you lived before? Can you tell me some reasons why/why not?

Activities

- Tell me a bit about how you like to spend your time.
- Do you like going into town for shopping and things like that?
- Tell me about any hobbies or activities that you enjoy. (Probe in relation to activities as part of a group, where they take place etc.)
- Are you able to do all the things that you enjoy doing? (Probe in relation to reasons why/why not, issues such as time, transport, supports)

People

- Tell me a bit about the important people in your life? (Probe in relation to people who share the home, friends, family and support workers as appropriate)
- Who do you like to spend your free time with?
- What kinds of things do you do together?
- Tell me about the people in your life that help and support you to live in the community?
- In what ways do these people help and support you? (Probe for activities in the home and in the community)
- If you had any problems, who are the people you would ask to help you?
- How does it make you feel knowing there are people who can help out if you need them?
- Can you tell me about some ways that you also help and support the people in your life? (Probe in relation to activities in the home, groups involved with, family etc.)
- How does helping people and being part of the community make you feel?

Policy

- Do you think people should be able to make choices about where they live?
- Can you tell me why you think choice is important?
- What are the best things about living in the community?
- Are there any things that you would like to change to make them better?
- Are there any things about living in the community that you don't like or find difficult? (Probe about services such as transport, particular tasks etc.)
- Thinking about the future, would you like to stay living where you live now? Why would you like/not like to stay here? (Depending on response probe about alternative preferences)
- Again thinking about the future, would you like to stay living with other people?
- As people get older, do you think they sometimes need more help and support? (Probe in relation to types of support)
- As people get older, do you think it is important that they keep their friends and stay active in the community? Why do you think that?

Conclusion: Is there anything we haven't talked about that you'd like to tell me?

Appendix K: Interview Guide – Phase Two

Interview Guide for Stakeholders

- Semi-structured interviews with stakeholders, policy and opinion makers from the ageing and disability sectors to be analysed thematically.

- Participants will be asked to share their perspective on community living.

General Themes to be explored in the interviews:

- Community Living
- Independent Living
- Article 19 UN CRPD (and its applicability to older people)
- Deinstitutionalisation and community supports/models of care
- Interdependence
- Lifecourse
- Ageing in Place

Ideas to be addressed in greater detail:

Community Living:

- How do you conceptualise community living/how is it conceptualised by members of your representative organisation?

- Do you feel that community living means different things to people at different stages of the life course?

    - do you see a divide between older and younger people in terms of their needs?

- What do you think are the key factors for successful community living?

    - Services and services? What are most vital?
    - Employment?
    - Personalisation (both budgets and services)
    - Advocacy?
    - Choice and control?

- What do you think are the current main barriers to community living for older persons with disabilities?

Policy:

- What do you feel are the commonalities in ageing and disability that would speak to the rational for a non-cohort specific policy for community living?

- From your experience, do you feel that a life course policy framework for community living would deliver better outcomes for both older people and persons with disabilities?

    - A policy that was not delineated by age.
    - Disability can be acquired at different stages of the life course.

- What key elements would you like to see contained in a life course policy framework for community living?

    - Advocacy?
    - Personalisation of funding/services?

- What do you feel are the main barriers to greater policy cooperation in the ageing and disability sectors?

Appendix L: Case Illustration Profiles – Phase One

Participant	**Matt**
Age	86
Disability	Physical – mobility impairment
Geographical Location	County Galway – rural area
Marital Status	Widowed
Living Arrangement	Lives alone in own home
Children	Yes
Grandchildren	Yes

Matt is 88. He was widowed in mid-life and raised his children. He is a retired manual worker and by his own admission he lived a hard life in all respects. He lives alone in his own home in the countryside. He has aged into disability and attributes some of his current physical impairments to his hard physical working life. Matt has a good relationship with his six children and takes pride in their achievements and takes their losses to heart. Matt is reflective about his life, the past and the events and transitions that brought him to his current situation of widowhood, disability and older age. He has moments of melancholy, especially when remembering the past. However, Matt is also resilient and is determined to get on with things for as long as he can. He receives informal support from his adult children. He has also engaged formal home support on a private basis to help with household chores. He attends a community day centre in the locality. He enjoys spending time with his family and especially loves his grandchildren, who are a positive influence in his life.

Participant	**Frank**
Age	52
Disability	Intellectual
Geographical Location	Urban Town
Marital Status	Single
Living Arrangement	Shared group home with 3 others
Children	No
Grandchildren	No

Frank is 52. He is single and is not very close to his family. He has an intellectual disability and has de-congregated from an institutional setting to a group home in the community. He is happy with his current living arrangement. He enjoys his life in the community, socialising and attending courses such as cooking classes. He has a part time job and enjoys meeting people. He also appreciates the sense of purpose and responsibility that employment gives him. He is reflective about his life, both his past and his future. He contrasts his life in the community with the lack of opportunity and independence he experienced in his former residence. He is determined to maintain his independence in the community.

Participant	**Eithne**
Age	93
Disability	Physical – mobility impairment
Geographical Location	Rural
Marital Status	Married
Living Arrangement	Lives with partner
Children	Yes
Grandchildren	No

Eithne is 93 and lives with her spouse, who has dementia. She lives in a rural area. She came to live in Ireland with her spouse in later life. She has a good relationship with her home helps, who are very supportive of her. She also has a diverse social network. She has friends with whom she socialises and she also attends a community day centre. She is keen to stay both physically and mentally active. She wants to maintain her independence and remain living in her own home. Eithne has a positive outlook on life, despite a somewhat difficult home situation. Eithne is reflective about her past and the changes she has experienced. She has a fierce determination to make the best of her situation come what may.

Participant	**Catherine**
Age	77
Disability	Sensory
Geographical Location	Urban
Marital Status	Widowed
Living Arrangement	Alone
Children	Yes
Grandchildren	Yes

Catherine is 77. She is widowed and lives alone. She has six children, some of whom are living in the locality. She receives informal support from her family. She also has grandchildren with whom she has a warm and loving relationship. She is not very socially active and attributes this largely to her disability. She likes her neighbourhood and home. However, she is nostalgic for times gone by when neighbours were more involved in one another's lives and her children's friends would have been calling to visit. She believes that people were more connected socially in the past. She is reflective about her current situation and is determined to maintain her independence and autonomy for as long as she can. She asserts her independence by undertaking tasks such as shopping on her own. However, this is difficult with her disability. She is reluctant to use any visual mobility aids, as she believes this is giving in to her disability. She also believes that it is an admission that stigmatises her and puts her in a vulnerable position vis-a-vis her interactions with others in the community.

Participant	**Brigit**
Age	84
Disability	Physical and Sensory
Geographical Location	Suburban
Marital Status	Single
Living Arrangement	Alone
Children	No
Grandchildren	No

Brigit is 88. She never married and does not have children. She was a professional and her path to retirement was gradual. She lives alone in her own home in a suburban housing estate. She aged into disability having a sensory (hearing) and physical (mobility) impairment. She feels supported by her neighbours and has a good relationship with her nieces and nephews. She is a member of a variety of local groups including a drama club and an active retirement club. She feels a personal responsibility to remain active in her community and also to maintain her independence and has engaged in adaptive strategies including home modifications. She is reflective and has considered both the ageing and disability aspects of her identify and the wider policy implications at both an individual and a societal level.

NODES	SEGMENTS OF TEXT
Slowing down after illness Making the best of current situation Making changes after incidents Filling the void left by loss **Displaying innovation in managing disability** Being resourceful despite limitations Adapting to new realities of disability Adapting to being alone	*You know when you are just on the social welfare pension and you try to work ways around those things. There is a lot of things now that I have overcome, like things I cannot do for myself but I keep on trying until I get it. I find a way around it and it works for me.* *You know if I can't wash my own hair because I wouldn't be able to do it then so I just go across the road, there is a hairdresser. I've been going to her once a week and that's grand* *See I'm in a great position. There have been times when I wouldn't be able to go out shopping but I can do it online and it would come here.* *I have a makeshift kind of one of them linen wardrobes that artists do have. I put pone of them over the commode in the hall. So that I don't have to climb stairs during the day you know.*
Adapting to changing Circumstances	
Responding to New Realities	
RESILIENCE	