Disability – an Issue for All Ages: A Study of the Experience of Disability and Ageing

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Key Abbreviations:

DwA: ‘disability with ageing,’ experiencing disability with ageing having lived relatively disability free until reaching mid-life or late-life.

AwD: ‘ageing with disability,’ experiencing ageing having been born with disability, or having first experienced disability in childhood, young adult or adult years.

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Abstract

This study explores subjective experiences of disability with ageing and ageing with long-term disability and the separate organisation of public policies on ageing and on disability that in part shapes those experiences. Using a constructivist grounded theory methodology, this study includes rich interview data from interviews with 50 older people. It also includes data from interviews with 16 people working on disability or on ageing. It can be placed within the theoretical frame of critical gerontology and it is informed by a social constructionist approach to the lifecourse. The study makes an original contribution to the field of critical gerontology by providing evidence to challenge assumptions and policies about older people through an exploration of disablement processes, meaning in life, and public policy approaches on ageing and on disability. It engages with concepts from critical disability studies, with a biographically embodied approach to chronic illness, and with literature on meaningful orientations in life. The study calls for more links between the fields of disability and ageing.

It finds that older people experience disablement in their bodies and in their contexts, which, often combined with losses of intimates, challenges their sense of meaning in life. How they respond amounts to a challenging process of trying to remake lives that they perceive as meaningful. By showing, through an inductive analysis, how older people experience disability, the study evidences how the subjective experience of disability in older age is consistent with a biopsychosocial model of disability (where disability is the outcome of the interaction between individual and contextual factors), and, thus, to a model, applied within the field of disability but not of ageing. It also shows how separate frameworks for policy on ageing and disability contribute to keeping in place medicalised, reductionist notions about the nature of disability in older age. The study's findings point to the usefulness of applying a biopsychosocial model of disability to the field of ageing.

The study compares two groups that are assumed to be very different (those experiencing disability with ageing and those ageing with disability) and suggests that the *outcomes* both groups want for their lives are similar, and that many of the difficulties and barriers faced are similar.

The study challenges societal responses to disabled elders, specifically narrowly-focused policy and community responses that ignore the full range of their needs and aspirations for meaningful lives. It supports suggestions that a counter-narrative of ageing and the lifecourse is needed, one that can integrate disablement processes as a ‘normal’ part of life, and that can recognise both the challenges of disablement processes in older age *and* the ongoing efforts of disabled elders to perceive value and meaning in their lives.

PROLOGUE – SPEAKING PERSONALLY

I start this thesis with a personal prologue. I had worked in the area of ageing for almost two decades before embarking on this study. There was one experience from my early days that I continued to think about during subsequent years. It had raised questions that seemed obvious, but also more intractable and paradoxical than other ambiguities about the ageing experience that colleagues and I frequently discussed.

The experience was of attending a meeting that had been organised by disability organisations and attended by representatives of a few age-sector organisations. The representatives from the disability side were seeking support for a lobbying campaign focusing on promoting accessible buses. The oldest person at the meeting was an active woman in her 80s. She rejected the suggestion that there was a basis for cooperation, saying that she had no trouble ‘hopping’ on buses.

This raised questions with me that I couldn’t fully articulate about what disability was and whether ageing and disability were related. These questions surfaced again years later when I came to think about undertaking further study. By then that woman had ceased to be involved in age-organisations, had moved to a nursing home and died. And I had seen other older people who had been extremely active in different age-organisations experience illnesses and/or disability, and reach a point of withdrawing from, or being encouraged to withdraw from, organisations that they had led and that had been a significant part of their lives.

I began to see that transition as the most dreaded and consequential one of later life, part of a process with inexorable aspects to it that were routinely feared, denied or played-down. I began to wonder about the reasons for this and its consequences.

I originally conceived of this study as exploring the experience of older people first experiencing disability in older age, because their experience was the one I was most familiar with. However, when I started to read about the issues involved and to talk to others about them, I became at least as interested in a second group – those who are ageing having experienced disability over a long period of time. The experiences of these two groups are what this study explores.

CHAPTER 1: INTRODUCTION

This study engages with disability and ageing from a sociological perspective, two areas that are usually approached separately in research. Looking at them together highlights a series of paradoxes in policy and activism, theorising and conceptualisation. It also suggests that the subjective experience of disability in older age is not well-understood in either field, with under-developed theorising and gaps in empirical evidence about the subjective experiences involved.

I start by discussing these paradoxes and suggest why there is a need for research that seeks to cross boundaries in scholarship. I then present the study's aims and research questions and its location within the academic field. Because the issue of terminology is complicated and contested on disability, I discuss terminology before summarising the study's key findings. This Introduction ends with a Chapter by Chapter outline of the rest of this study

1.1. Paradoxes in Theorising and Conceptualisation, Policy-making and Activism

Before outlining the study's research question, I address the fact that a series of paradoxes are at the heart of this study. These are seen in separate approaches to policy-making and activism on disability and ageing, and in separate approaches to theorising and in how disability is understood – a key distinction in each of these being that social processes are more emphasised within approaches to disability and medical ones within approaches to ageing.

This means that despite impairment being often considered a social norm of ageing, or perhaps because of it, older people with impairments are rarely regarded as 'disabled' in quite the same way as children, or younger adults might be (Kennedy and Minkler 1998:757; Priestley 2002; 2006). And despite the fact that disabled people will age, and most who are ageing will experience disability (Zola 1989a; Garland-Thomson 2016), there are no theories addressing both ageing and disability, but instead separate theories on ageing and on disability, something that impacts on our ability to conceptualise relationships between the two (Putnam 2002; Murphy *et al.* 2007).

Yet the lack of acknowledgement of disability in older age was highlighted decades ago by influential voices from gerontology (Townsend 1981b; Walker 1981b), disability studies (Abberley 1987; Wendell 1996) and medical sociology (Zola 1989a,b). For example, Townsend (1981b:97) argued that the needs of older disabled people were insufficiently acknowledged, which he attributed to a tendency to categorise 'the 'elderly' as separate from 'the disabled'. Abberley (1987:15) argued that levels of disability in society were minimised by overlooking disability associated with ageing, and Wendell (1996:18-9) argued that reduced opportunities experienced by older people were no more attributable to 'nature' than those experienced by non-elderly disabled people. But others took a contrary position. Amundson (1992:115), for example, made a distinction between 'age-frailty' and 'disability', arguing that to do otherwise 'falsely depicts handicaps as a natural and expected part of human existence'.

More recently, a range of scholars writing on ageing call for closer links with scholarship in disability (see Kennedy 2000; Oldman 2002; Putnam 2007; Kelley-Moore 2010; Grenier, Griffin and McGrath 2016; McGrath *et al*. 2017) and for closer links to scholarship in medical sociology (Higgs and Rees-Jones 2009). And some scholars from disability studies recognise the need to engage with disability across the lifespan (Priestly 2003a;2006; Davis 2013a; Shakespeare 2014a). International experts in a range of disciplines suggest that bridges in research, policy, and practice across the two fields are critical to address both demographic ageing and the longevity of those ageing with long-standing disability (Bickenbach *et al.* 2012). However, these bridges are limited in practice (Salvador-Carulla *et al*. 2009).

The Paradox of Separate Policy-Frameworks and Practices

Public policies have important consequences in the fields of both ageing and disability. Policy environments can shape membership categories that affect identity (Hendricks 2010). Thus, policies define 'the parameters of legitimate ageing' and shape personal identities of older people (Estes, Biggs and Phillipson 2003:4,67). The very emergence of older people as a distinct category is associated with the development of pension policies (Conroy and Mangan 2006; Moody and Sasser 2012). Likewise, disability can be organised by public policies that can turn some transitions into 'strongly demarcated events' (Mayer 1986:167; Marshall and Mueller 2002).

Separate policy-fields operate in the areas of disability and of ageing. Thus, public policies tend to suggest that people are either disabled or older, but not both (Bigby 2008), and a person who is disabled at age 64 may be simply categorised as 'old' at age 65 (Kelley-Moore 2010:104). Complexity and confusion are associated with these separate administrative categories (Priestley and Rabiee 2001; Putnam 2007).

The phenomenon of significant numbers ageing with disability is a relatively new one, creating, what Putnam (2002) calls, a new category of older adults. The policy-framework in many countries is not well developed for them (Bigby 2002; Anand *et al*. 2012; Raymond, Grenier and Hanley 2014). They may have difficulty accessing specialised aged-services and the experience of those who age prematurely may be overlooked (Bigby 2008; La Plante 2014). They sometimes also perceive that professionals within older people's services do not understand their impairments (see Cooper and Bigby 2014; Simcock 2017).

Further discordances are introduced by the current influence of positive ageing approaches (in 'successful', 'active' or 'productive' forms) on international policy-frameworks on ageing. In these approaches, 'successful' ageing is viewed as incompatible with ill-health or impairment (Estes, Biggs and Phillipson 2003:67). The focus is on the third age (West and Glynos 2014), and they risk marginalising disabled older people within an active participation policy agenda (Raymond and Grenier 2013).

The Paradox of Separate Political Movements

Despite sharing concerns about issues such as housing, transport, income, choice and dignity, representative groups of older people and disabled people remain separate (Priestly 2002:368). Disability activists tend to enter the movement at a young age and disabled older people tend not to be involved (Shakespeare 2006:75). Issues that are pursued tend to be those affecting people of working age (Priestley 2003a; 2006; Shakespeare 2006; Thomas and Milligan 2018). For their part, representatives of older people often focus on active ageing, and both movements distance themselves from the negative imagery of dependency in deep older age (Priestley 2006). Thus, 'mutual discrimination is to some extent present in the very struggle against ageist and ablest norms' (Jönson and Larsson 2009:75).

The Paradox of Separate Theorising and Conceptualisations (or Models) of Disability

Conceptual models define disability, help shape self-identities and determine the professions involved (Smart 2009), and separate models are employed for understanding disability within the two sectors. Biomedical approaches dominate the field of ageing, while social models of disability have been influential in approaches to disability, which means that disability (as applied to children and younger adults) is seen as a social problem not wholly an individual one (Priestley 2003a). Bio-psychosocial models, having their origins in medical sociology, attempt to bridge medical and social models.

But organismic ageing processes still dominate the explanatory framework for disablement in older age, overlooking social structural influences (Estes, Biggs and Phillipson 2003; Kelley-Moore 2010:107). Medicalised approaches characterise ageing as 'processes of decline and decay' (Phillipson 2013:132) and sociological understandings as applied to late older age (when disability is more prevalent) are at an early stage of development (Grenier 2012; Phillipson 2013:128). Furthermore, the framing of the ageing process as one of 'decline and decay' may contribute to a lack of understanding of subjective experiences of disabled older people (or those considered to be living in the fourth age[1]) (Phillipson 2013:132; Lloyd *et al.* 2014). Instead, existing literature places a large emphasis on identifying objective conditions of frailty (Grenier 2012). Thus, empirical work on subjective experiences of being older and disabled is limited (Kelley-Moore *et al.* 2006; Nicholson *et al.* 2012).

There are similarities in the course that theorising has taken in gerontology and disability studies, and critical scholars in both fields now identify cultural, discursive and relational issues common to disabled people and older people. Yet most critical approaches focus *either* on disability or ageing (Grenier, Griffin and McGrath 2016). Older people have largely been left out of debates in disability scholarship (Priestley 2006; Shakespeare 2014a).

Thus, between the biomedical construction of this period as one of 'decline and decay' (Phillipson 2013:132) and the dominant transition of work to retirement portrayed as one of activity and leisure, more difficult transitions – such as experiencing impairment or disability – remain unacknowledged (Grenier 2012). And little is known about the experience of ageing with long-standing disability (Jeppsson-Grassman *et al.* 2012). An implication is that if gerontology is reluctant

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[1] The third age is conceived of as a time of freedom to pursue goals and lead a creative, fulfilling life (Laslett [1989]1996), characterised by health, personal growth and active engagement (Lloyd 2015). By contrast, the 'fourth age' is understood as about decline and disengagement (Laslett [1989]1996).

to engage fully with the difficult issues of impairment, disability, and ultimately death, and disability studies are also unwilling to address ageing, then older people truly are, as Grenier (2012:182) says, ‘left on their own to negotiate these changes’.

Overall, it continues to be unclear whether the meaning and experience of disability in older age can, or should, be considered as in any way different from disability in younger adulthood or childhood (Priestley 2006). And it also remains unclear whether the social processes of ageing with disability are different from those involved in first experiencing disability in older age (Putnam 2002; Freedman 2014). I explore both the experience of ageing with disability (**AwD**) and the experience of disability with ageing (**DwA**) in this study.

1.2 Some Ways Forward?

As a motivation for attempting to bridge the fields of ageing and disability, Townsend (1981b:93) identified benefits from a focus not on bodies alone, but on the *outcome* of limitation for the individual (his emphasis). As he argued, shifting the perspective from the individual/biological to the contextual creates more room for seeing the potential of the individual.

While disability can be understood as a negative, stigmatised identity position, it involves much more than that (Goodley 2014). As Goodley (2014:xi) says: ‘Disability asks us to consider what we value in life’. This points to the profound nature of the issues that are at stake. West and Glynos (2014:13;14) highlight the need not to repress the uncertainty associated with the last stage of life and to enable those involved to engage in ‘processes of collective judgement making’. And Titchkosky (2000) suggests that disability must be regarded as a place not only to be spoken about but from which to speak and learn about the human condition.

Arguably, issues of disability and ageing are already intertwined. As Riddell and Watson (2003:16) suggest:

> There is no point in developing positive images of disabled people if older people continue to be socially devalued.

This statement, and its converse, form an implicit proposition of this study – that there may be no point in developing positive images of older people if disabled people continue to be socially devalued. However, a more unified agenda between the two fields will likely need, as Zola (1998a; 1989b:401) argued, a reorientation in general thinking about disability, and, I suggest, about ageing also.

It is notable that scholarship in gerontology has started to draw on concepts from critical disability studies and to apply them to the experience of disability in later life (see McGrath *et al.* 2017) or to dominant discourses of ageing (see Gibbons 2016 on ‘successful’ ageing). In addition, critical scholars now challenge binary approaches within both disability studies and gerontology. Their assertion of the need for a realistic engagement with the nature of humanity (including both limitations and possibilities) in both fields may signal potential for a more unified approach to scholarship in the future.

For example, writing within disability studies, Davis (2002:32) suggests that ‘the only universal is the experience of the limitations of the body’. Shakespeare (2014a:60-8) contends with orthodoxies associated with both the social model of disability that exclude accounts of the body and with cultural disability studies that suggest that impairment is *only* a matter of discourse. Instead, while he values an emphasis on disabling societal factors, he argues that disability is an interaction between individual and structural factors, which means that bodies *and* society disable people (Shakespeare 2014a:74-80). He highlights the need for responses that are informed by lived experience, that account for a human nature that has limitations and vulnerabilities and is ultimately mortal, while also acknowledging that life with disability can involve possibilities for adaptation and flourishing (Shakespeare 2014a:74-5,87). He emphasises the impact of impairment, which can be negative in itself (not just a matter of discourse or labelling), suggesting that scholars discussing impairment should base their analysis ‘on empirical evidence about how disabled people feel about their embodiment’ (Shakespeare 2014a:67). He also apprehends disability as an issue that occurs across the lifespan.

Somewhat similarly, from within critical gerontology, Baars (2010:115) argues that a cultural tendency to ignore finitude and limitations can exclude both disabled people and older people. Grenier, Lloyd and Phillipson (2017) argue for responses to ageing that develop from acknowledgement of fragility and limitations rather than approaches organised exclusively around concepts of productivity, success, and activity. Other critical gerontologists highlight the need to engage with real bodies of older people (Holstein and Minkler 2007:17-18), and to bear witness to the sufferings of older age, which Gilleard (2018) argues, may help give meaning to what would otherwise be meaningless suffering.

Critical/cultural scholars are now emphasising the importance of meaning for older people and, relatedly, the limitations inherent in dominant discourses on ageing (‘decline’ and age-defying). Crucially, Baars (2017) suggests that ageing is drained of its ‘meanings’ by the idea that life becomes residual beyond hectic adulthood. Baars (2017) argues that there is a basic deficit in approaching ageing due to the lack of recognition of vulnerabilities and limitations, on the one hand, and of potential for creativity and fulfilment, on the other. The meaning we give to our lives is affected by illness/impairment (Holstein 2015) and the desire to meet self-realisation or actualisation needs is likely to grow with age (Thompson 1992; Dannefer and Lin 2014). However, the need for meaningful orientations in life may go unrecognised for disabled elders (or those in the so-called ‘fourth age’), partly due to the link made in dominant discourses between absence of impairment and able-bodiedness with personal growth and engagement.

Therefore, societies need to accept that impairment is part of most lives (at some point in the life span), that similar cultural concepts, ideals and practices devalue and marginalise disabled people of all ages, that human lives can involve poles of limitation and creativity simultaneously, and that the need to perceive that one’s life has worth and meaning applies to people at all ages and with all kinds of impairments.

Thus, I suggest that there is value in attempting to bridge different fields or at least to open up conversations between them, specifically the fields of ageing and disability (including approaches within medical sociology). I argue for this for analytical and theoretical reasons, for practical reasons related to policy-making and service-delivery, and for the potential it offers to make common cause between groups of people who are otherwise divided, and amongst whom there are individuals on their own dealing with issues that require collective responses. I argue for this, not so that ‘disability’ as an identity should be reinforced as an end in itself, but so that we can be better served by realistic, inclusive approaches to the human condition across the lifecourse. I do so because when we do otherwise we overlook what is most fundamental to our humanity – our need for meaning and our essentially vulnerable nature – which we would be better-off accepting, learning from and accommodating.

1.3 The Study: Aims and Research Questions

This study aims to make a contribution to knowledge by exploring subjective experiences of disablement amongst older people and the meanings made of those experiences. The main focus is those experiencing disability with ageing (DwA) and those ageing with long-term disability (AwD). The study also explores the separate organisation of public policies on ageing and on disability and the consequences of this separation for older people. Thus, the study was sequential in design, involving interviews not only with older people but also with people representing statutory and non-statutory organisations in Ireland, which allows for exploration of the nature of the divisions between policy-frameworks on ageing and disability and the consequences for older people.

This is a qualitative study using biographical narrative and a constructivist grounded theory method to study experiences (and meanings made of experiences) of disabled older people. It also included a small number of older people not experiencing disability for comparative purposes. I recruited participants from those living in their own homes and communities in urban and rural Ireland and focused on the experience of physical and/or sensory disability. I conducted 53 interviews with 50 older people and interviewed a further 16 people working on ageing and disability. (In **Chapter 5**, I provide more detail on participants and on methodology.)

Being inductive, the study did not set out to prove a hypothesis but started from the idea that disability in older age involves two groups – those first experiencing disability with ageing and those ageing with long-standing disability, separate categories that are recognised in scholarship, and that are in-part constructed by the separate approaches to policy-making on ageing and disability outlined already. Initially I envisaged exploring disablement processes with the DwA group and ageing processes with the AwD group[2] as that reflected empirical studies with both groups (discussed in the literature review in **Chapter 3**).

However, through an inductive, interpretive analysis, I found that the disability experiences of the AwD group were not in the main as static as this formulation

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[2] Early on I framed the research questions as: (1) What meanings are made of the disablement process first experienced in older age? (2) What meanings are made of ageing and the interaction of ageing and disability by persons ageing with long-term physical disability?

envisaged[3], and that there were many shared and overlapping experiences between the two groups. That is to say, both groups experience disablement processes as they age, the difference being that the AwD group experiences additional impairments and/or worsening conditions on top of existing impairment. I reformulated key research questions that crossed both groups, and I also carried out a comparison between the two based on the findings from my inductive analysis.

The following are the key research questions addressed through an inductive grounded theory study with older people:

- How do older people experience disablement processes and what meanings do they make of those experiences?
- How do disabled older people respond to the challenges involved?

Following inductive analysis that explores the above questions, I also compared the experiences of the two main groups, and I include a comparison **(Chapter 10**) in which I draw on my inductive analysis to address the following:

- Are the social processes experienced by those experiencing disability with ageing different from those ageing with disability?

Given the role of public policies in shaping lives and identities and even in creating categories of people, this study also included a focus on those working on ageing and disability in Ireland (policy-makers, service providers and activists). The following were the research questions for that part of the study:

- How does the chronological boundary of age 65 operate between services for disabled people and older people in practice?
- How do people working in these fields relate to this separate organisation of services?
- What are the implications for disabled older people?

1.4 Placing this Study

This study can be placed within the theoretical frame of critical gerontology and it is informed by a social constructionist approach to the lifecourse. Critical gerontology is ‘a more value-committed approach’ to social gerontology, involving a commitment not just to understand the social construction of ageing but to change it (Phillipson

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[3] The experience of long-term disability, while sometimes thought of in static terms, is a dynamic process (Burchardt 2000:4). That was suggested by several empirical studies (reviewed, **Chapter 3**) and how I found that many of this study’s participants experienced it.

and Walker 1987:12). Thus, Bernard and Scharf (2007:6,8) characterise critical gerontology as providing evidence to challenge assumptions and beliefs about ageing, old age and older people, contributing to understanding ‘varied dimensions of difference’.

There are two strands of critical gerontology, known as political and moral economy (the latter including cultural or humanistic approaches). This study draws on both strands. The emphasis on how institutions and policies shape lives and categories of people can be said to align with a political economy approach. This study’s emphasis on the subjective experience of older people means that it aligns especially with a moral economy approach (or cultural approach) because of how that perspective explores questions about meaning, asking how older people make sense of their experience and how tacit or explicit cultural ideals shape that experience (Holstein and Minkler 2007). (I discuss these approaches in **Chapter 3**).

The study is informed by a constructionist lifecourse perspective (outlined in **Chapter 3**), to focus on the subjective experiences of participants and how experience is made meaningful in relation to the passage of time (Holstein and Gubrium 2000:41)

I engage with scholarship on meaning in life (from cultural gerontology and from social psychology) to interrogate meaning-making processes. I interrogate identity practices in context, drawing especially from a biographically embodied approach to chronic illness[4] from medical sociology, and I draw on concepts from critical disability studies to help make sense of disablement processes. Thus, the study is informed by theoretical models drawn from separate fields, especially of ageing, disability and lifecourse studies, and it brings them into a critical conversation. By doing so, the study highlights assumptions and some weaknesses of each and also points to areas of potential linkage between them. In this way, as well as through its empirical findings, it makes a contribution to knowledge.

In empirical terms, the study is informed by studies that explore subjective meanings made of physical and sensory disability (or cognate notions like ‘frailty’)

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[4] The chronic illness focus is relevant because it is associated with impairment; chronic illness is also the largest single cause of disability in older age (See Department of Health and Children 2008:24 and **Chapter 3**).

amongst those experiencing disability with ageing, and by those that explore the experience of ageing amongst people ageing with disability. These come from different fields/disciplines, including social gerontology and nursing, and, to a lesser extent, disability studies and medical sociology. I review these studies in **Chapter 3**. As already indicated, it remains unclear if the social processes of ageing with disability are different from those involved in first experiencing disability in older age. There are very few studies that explore the experiences of the two groups together from a sociological perspective, or that compare them, as this study does.

1.5 Terminology and Abbreviations

The meaning of 'disability' is contentious (Townsend 1981b; O'Donnell 2007). Choice of terminology can distinguish 'allies from enemies' with 'disabled people' signaling a social model approach and 'people with disabilities' signaling a mainstream approach (Shakespeare 2013:217). Acknowledging that all terms and definitions are imperfect and can be contested (Graby 2015; Garland-Thomson 2016), I use the phrase 'disabled people' as it is used amongst scholars/activists in the U.K., who use it to shift the focus from the individual to society (Morris 2001; Priestley 2003a).

I adopt a bio-psychosocial definition of disability (which I discuss in **Chapter 2**). In this approach, disability is said to arise from the interaction of individual conditions with contextual factors, which are personal and environmental. It is consistent with approaches within medical sociology and critical disability theory (see Shakespeare 2014a; Hosking 2008). Thus, 'disability' is *relational* – it includes, but is broader than, 'impairment', which is defined as problems in body function or alterations in body structure.

There are some terms that are important to this study. The first, '**disability with ageing'** (abbreviated to **DwA**) is used of people who live relatively impairment free until reaching mid-life or late-life and experience age-related conditions (Verbrugge and Yang 2002). The terms 'late-life disability' or 'ageing into disability' also refer to this experience[5].

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[5] At European level the Council of Europe has opted for different terms, which are also cumbersome: 'ageing people with disabilities' meaning those who grow older having experienced disability for much/all of their lives and 'older people with disabilities' meaning those experiencing disability at a relatively advanced age (Council of Europe Committee of Ministers 2009)

The term ‘**ageing with disability’** (abbreviated to **AwD**) is used of people who are either born with or acquire some form of impairment in their childhood, young adult or adult years (Verbrugge and Yang 2002). The terms ageing with ‘lifelong’ or ‘long-standing’ disability also refer to this experience. (I elaborate further on these issues in **Chapter 5** when I discuss recruitment of participants).

I will sometimes also use the term ‘disabled older people’ or ‘disability in older age’ by which I mean to refer to the experience of both groups.

1.6 Study Findings and Implications

The key finding of this study is that older people experience disablement in their bodies and in their contexts, which (often combined with losses of intimates) challenges their sense of meaning in life and that they respond by trying to remake lives that they perceive as meaningful.

Disabled older participants experience disablement both at a bodily level (though they don’t define themselves by their bodies) *and* at the level of interactions with contexts such as physical environments and prejudice of others. Thus, their experiences of disablement are broader than the biological processes that dominate explanations of impairment or disability in older age – in theorising and in policy frameworks.

That bodies could be perceived as disabling or limiting (or more disabling or limiting for the AwD group) is not surprising. But participants experienced consequent suffering and loss, uncertainty about daily life and the future, changes in relationships and fears of ever-greater dependency and forced abandonment of social activities and roles. They could also perceive (and resist) exclusion from participation opportunities and consignment to a discredited social category. I found that all of this can involve a fundamental re-thinking of biography and self-concept, even when disablement (or worsening disability) occurs gradually and at a stage in life when participants consider impairment as ‘normal’ or ‘on-time’.

I show how participants respond to the challenges that disablement onset (or worsening) involves. This was often also experienced simultaneously with (and partly constituted by) losses amongst their family and social groups. I demonstrate that participants respond with attempts to restore order following disruption, or to remake lives that make sense – by which I mean that they act to try to reorient their lives so that they could perceive them as meaningful. In this effort, some were successful, others frustrated. Public policies and community organising were often important enablers of their efforts.

Comparing the two groups (DwA and AwD), I found that there were some differences between them. However, both groups wish for similar *outcomes* for their lives, and many of the difficulties and barriers faced are similar. Both groups seek connection with others, want to be included in the mainstream and engage in efforts to have lives that they perceive as meaningful. Key differences between the two groups arise from sociocultural meanings made of impairment at different stages of the lifespan – and this occurs as part of larger societal and cultural processes in which constructions of ageing and of disability, and the social devaluation of each, are intertwined.

Finally, through interviews with policy-makers and others working on ageing and on disability, I found that separate frameworks for policy on ageing and disability contribute to keeping in place medicalised, reductionist notions about the nature of disability in older age. This is reinforced by the lack of a language for, and the lack of a concept of, disability first experienced in older age (with disabled older people often thought of as ‘just ‘elderly’). This affects disabled older people by influencing how services for them are conceived of, and it suggests that one is either ‘disabled’ or ‘older’ not both. This, in turn doubtless influences how older people view themselves as well as determining the type of public services they receive.

Turning to the implications for scholarship, by focusing on how disabled elders interpreted change and reacted to it, this study makes an original contribution to gerontology. The finding that disabled older people engage in challenging, dynamic processes of trying to remake their lives so that they could perceive value and meaning in them challenges some assumptions or informing paradigms of the academic fields that I engaged with. Specifically, it challenges normative notions about the nature of the lifecourse, especially about the residual nature of the so-called fourth age and of the presumed division between third and fourth ages. Changes can be experienced as challenging (involving ongoing processes of interpretation and reinterpretation) and the wish to continue to perceive that life has value and meaning can elicit courageous and creative responses. Thus, the transitions experienced in older age are more complex and various than those that have to-date received most attention in scholarship. The study highlights some of their socially-constructed aspects, which are yet to be fully recognised. Thus, the study's findings also challenge solely biological explanations of impairment in older age that dominate gerontology, and the tendency within disability studies not to engage with disability experienced in older age. Highlighting how similar cultural ideals and fears that deny human vulnerability and limitation devalue both older people and disabled people, the study challenges the extent of the divisions between the fields of ageing and disability and suggests the need for scholarship within each field to engage more with scholarship from the other. In short, it points to the need for the emergence of a counter-narrative of ageing and the lifecourse that can integrate disablement processes as a 'normal' part of life, and that can recognise both the challenges of disablement processes in older age *and* the ongoing efforts of disabled elders to perceive value and meaning in their lives.

That disabled elders are engaged in processes of remaking meaning in their lives also represents a challenge to society, specifically to community and policy responses that ignore the full range of their needs and aspirations for meaningful lives, and to bifurcated policy approaches to the third- and fourth- ages. It shows that the emphasis on the social within approaches to disability - that is part of theorising, that informs models of disability, and that underlies policy-frameworks - is as valuable for older disabled people as for disabled people generally. All of this suggests the need for greater appreciation that disability is an issue for all ages.

1.7 Chapter by Chapter Outline

Chapters 2-4 contextualise the study in different ways. Each can be considered to address a key paradox already identified (in conceptual models, in theorising, and in policies). **Chapter 5** presents the study's methodology and methods. Then the four Chapters that follow (6-9) present and discuss its findings based on an inductive, interpretive analysis. **Chapter 10** uses this analysis to compare the AwD and DwA experiences. Finally, **Chapter 11** summarises key findings and highlights some implications for policy and research.

In some more detail, here are the areas covered by each Chapter:

Chapter 2 contextualises this study by addressing the preliminary question of what disability is and if older people can be said to experience it. I adopt a biopsychosocial, or interactional, understanding of disability – as the outcome of the interaction between individual and contextual factors - and argue that this definition is capable of encompassing both the DwA and AwD groups within the category 'disabled'.

In **Chapter 3,** I discuss key theories of ageing and disability (concentrating on critical/cultural approaches) and lifecourse studies and I set out my approach to the lifecourse. I also review empirical studies of subjective experiences of disability amongst the DwA group and of ageing amongst the AwD group. My review suggests that sociological understandings, especially of the so called 'fourth age', are not well advanced, and that the related subjective experiences and lifecourse transitions are not well understood.

Chapter 4 reviews public policy-frameworks in Ireland on ageing and disability and discusses the interface (or lack of it) between the two. It contextualises this by reviewing international approaches, including some international examples of bridging between the two fields. It also presents some statistics on the prevalence and nature of disability in older age. This Chapter's findings confirm that the two policy frameworks construct ageing and disability as separate phenomena by suggesting that people are either disabled or older not both.

Chapter 5 outlines the study's empirical research design, including its methodology (constructivist grounded theory), methods and analysis. I also present an overview of the analytical concepts or categories that I identified in the study and the linkages between them.

Chapter 6 presents findings from interviews with policy-makers, service providers and staff of organisations representing older people and disabled people. I found that how disability in older age was understood (or rather the lack of a concept of disability with ageing) and the funding/administrative boundary between the two service-frameworks operated in a mutually reinforcing way. Together they could shape the perceptions of those working on ageing or disability in ways that legitimated how services are conceived of for disabled people and (separately) for older people. The Chapter also highlights anomalies in the way services are delivered in practice to older disabled people depending on the timing of disability onset.

Chapter 7 presents findings from interviews with older disabled people. It is the first of two that addresses their experience of disablement processes and the meanings made of them. It focuses on how participants perceived that bodies disabled them, though they did not define themselves by their bodies. Disability onset (or worsening) meant that most participants experienced a series of events that threatened their sense of identity, amounting to disruption of biographical assumptions, notwithstanding their perceptions of impairment/disability or 'decline', as 'normal' in older age. I discuss how participants negotiated their identity in light of two conflicting understandings of ageing in contemporary culture ('success' and 'decline').

Chapter 8 is the second of two Chapters addressing the experience of disablement processes in older age and the meanings made of them. I show that there are a range of contextual factors that contribute to the experience of disablement in older age. Participants (DwA and AwD groups) often felt disabled by social factors, environments, systems and attitudes that disable and/or marginalise all disabled people. Combined, the findings of this Chapter and of **Chapter 7** demonstrate that participants experienced disability in an interactional (or biopsychosocial) sense arising from the interaction of individual conditions with contextual factors. Feeling marginalised and being consigned to a discredited social category due to impairment onset contributed to the sense of biographical disruption (notable amongst the DwA group who experience this first in older age). I also discuss how similar cultural ideals associated with independent adulthood devalue both older people and disabled people.

In **Chapter 9,** I focus on how participants respond to challenges. I show how remaking a sense of meaning in life becomes a particularly important issue for disabled elders. This is due to the extent of change involved in disablement processes often experienced at a time when intimates die or become impaired. I show that older disabled people can respond to these twin challenges by engaging in a dynamic process of trying to make sense of their lives and of recreating the meaning structures of their lives, helped in some cases by public services and community organising. The third- fourth- age binary is not well marked in their self-perceptions and they can continue to identify with efforts to engage in activities, connect with others and to self-actualise, in a process that is essentially about having a sense of meaning in life and that is more typically associated with the third age.

In **Chapter 10,** I compare the two experiences – DwA and AwD – drawing on findings from the inductive analysis presented in the previous three Chapters. I suggest that there are commonalities in the two experiences – more perhaps than have been fully recognised to date. The *outcomes* both groups want for their lives are similar, and they also face similar challenges and barriers. Both groups aspire to connection with others, for inclusion in the mainstream and for having lives they valued or perceived as meaningful. Those who experienced disability for a long time could also be ageing with an accumulation of disadvantage (in health/impairment and in socioeconomic terms) though they were not the only ones to experience disadvantage. Many of the differences between the two groups arise from sociocultural meanings made of impairment at different stages of the lifecourse. These arise from a tendency to both fear and deny human vulnerability and limitation.

Finally, in **Chapter 11**, I summarise the study's findings, discuss its contribution to theorising, and I draw out some conclusions from the study to make recommendations for scholarship and policy-making.

CHAPTER 2: DEFINING DISABILITY

2.1 Introduction

According to Abberley (1998:79), the first thing you must do when writing about disability is ‘to clarify your terms and this immediately gets you into the realm of theory, since the most fundamental issue in the sociology of disability is a conceptual one.’ In this Chapter, I discuss definitions of disability and, in doing so, address one of the key paradoxes identified in the Introduction to this study – the fact that there are separate models used to understand disability generally and to understand it in older age. This contributes to keeping in place perceptions that older people are not ‘disabled’.

I first review how disability is understood within existing models of disability, involving two key models - social and biopsychosocial. I then discuss biomedical approaches, which still dominate definitions of disability in older age – where disability is understood as functional limitations or as ‘frailty’, and almost solely in an individual sense (rather than in a social context). Next, I consider sociological understandings of ageing, especially sociological approaches to the fourth age, which is a concept that may be said to correspond with much of the lived experiences that I explore in this study.

I argue that biopsychosocial understandings of disability – as the outcome of the interaction between individual and contextual factors - is a helpful way to define disability in older age, one that can encompass both those experiencing disability with ageing (DwA) and ageing with disability (AwD). This model is compatible with approaches to disability within medical sociology and critical disability theory (the latter having developed from social model approaches). It is also compatible with international approaches to the human rights of disabled people and with attempts to bridge the areas of disability and ageing in research, policy and practice. I argue for it principally because it could contribute to greater acknowledgement of socially constructed aspects of disability in older age.

2.2 Approaches to Defining Disability Generally – Social and Biopsychosocial

Disability is often understood within models that define it, determine which professions engage, and help shape self-identities (Smart 2009). The main models are medical (attributes disability to the person), social models (attributes disability to the environment), and biopsychosocial models (disability is relational - linked to the person-environment relationship) (Masala and Petretto 2010). While the social model of disability has been the dominant paradigm in researching and understanding disability (Dewsbury *et al*. 2004:145), this is not true of impairment experienced in older age, where the medical model has scarcely been challenged (Oldman 2002:795). This study is carried out from a sociological perspective, but, because of its dominance, I discuss how late-life impairment is understood within biomedical approaches, below. First, I look at social and biopsychosocial models as used to define disability generally.

2.2.1 Social Models

In this Chapter my focus is on definitions of disability, whereas a key focus of the next Chapter is theoretical approaches to disability. But there is some intersection between the two, because of how crucial definitions are in this field and the fact that disability scholars, whether for the social model or against it, are almost always in dialogue with it (Thomas 2004:573).

Until the 1990s, disability was conceived of in terms of rehabilitation, medicine, psychology, special educational needs and social work (Goodley 2011). Oliver (1996:31;32), who challenged the medical model from a social perspective in the U.K., characterised the medical model as ‘the personal tragedy theory of disability’. The U.K. social model goes back to a statement from 1976 on physical disability (which was subsequently broadened to include all impairments - Barnes 1998):

> '…it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (The Union of the Physically Impaired against Segregation and the Disability Alliance 1976:14).

This definition made a crucial distinction between the experience of impairment and the experience of disability – the latter being socially constructed - and it made a link to oppression. Crucially, ‘disablement has nothing to do with the body’ (Oliver 1990:45). Thus, the social model politicises disability and excludes accounts of the body (Goodley 2011:62).

Debates often focused on the impairment/disability dichotomy, which feminist and post-structuralist scholars, especially, criticize – while often also being supportive of social model approaches generally. They argue that the impairment/disability dichotomy is not representative of diverse lived experience (see Corker 1999; Corker and French: 1999; Shakespeare and Watson 2002; Shakespeare 2006; Anderson, Sapey and Spandler. 2012; Graby 2015). For example, Wendell (1996) and Crow (1996) argued that the effects of impairment such as pain and tiredness were disabling in their own right. For Hughes and Paterson (1997) a failure to theorise the impaired body hands the body over to medicine.

Overall, despite criticisms, the emancipatory aspect of the social model is acknowledged (see Tregaskis 2002) and even critics acknowledge its political usefulness (see Corker 1999; Bury 1997:137; Shakespeare 2006; 2013; Meekosha and Shuttleworth 2009). Shakespeare (2006:31; 2013) describes it as ‘one of the bravest and most transformative moves in the history of political thought’ because it turned traditional views of disability upside down.

The terms cultural disability studies or critical disability studies are used to signal approaches that move away from the preoccupation with binary understandings, while continuing to employ relevant aspects of social models (Shakespeare 2014a; Meekosha and Shuttleworth 2009). I discuss theorising within this perspective in **Chapter 3.**

North American and Nordic Models: Other social models exist. In North America, Nagi pioneered a view of disability where functional limitation is an expression of failure of environments to accommodate disability (Nagi, 1976; Masala and Petretto 2010) and Hahn (1993:46;47) expounded a minority group analysis. The impairment/disability distinction articulated in the UK social model was not central to the minority politics model (Goodley 2011). The Nordic relational model understands disability as a mismatch caused by individual difference *and* lack of adaptation of the environment (Shakespeare 2006:25, citing Tossebro). Thus, North American and Nordic models have not gone as far in redefining disability as ‘social oppression’, but both attempt to go beyond the medical or individual model (Shakespeare 2006:24; Masala and Petretto 2010).

2.2.2 Biopsychosocial Models

Biopsychosocial models attempt to integrate medical and social models. They introduce definitions rooted in medical sociology, associated with the view that disability can be caused by impairment at a bodily level *and* also by social disadvantage (Bury 1997; Thomas 2004). These approaches are associated with the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICFDH-2), 2001, (known as 'ICF'), which provides an international basis for definition/measurement on health and disability. It underpins the UN Convention on the Rights of Persons with Disabilities and the World Report on Disability (United Nations General Assembly 2006; World Health Organization, 2001; 2002b; World Health Organization and The World Bank 2011). 'Disability', according to the ICF classification, is:

> an umbrella term for impairments, activity limitations or participation restrictions (World Health Organization 2001:3).

The model is a biopsychosocial one because disability is said to arise from the interaction of individual conditions with contextual factors, which are personal and environmental. Personal factors include, for example, age, gender, social status, and life experiences; environmental factors include the natural and built environment, technology, support and relationships, attitudes and services, systems, and policies (World Health Organization and the World Bank 2011:5,307). Thus, 'disability' is *relational* (that is, occurring in the interaction between the individual and his/her context); it includes, but is broader than, 'impairment', defined as problems in body function or alterations in body structure (Bickenbach *et al* 1999; Bickenbach 2011:657).

Attempts at an international level to bridge fields of ageing and disability are associated with these approaches (See Weber and Wolfmayr 2006; Salvador-Carulla *et al* 2009; Bickenbach *et al.* 2012; Naidoo, Putnam, and Spindel 2012). And, writing in the Gerontologist, Hagestad and Settersten (2017:143) refer to the WHO approaches to definition in the context of later-life, because of its understanding of disability, not as a personal characteristic, but as a *relation* between individual capacity and environmental demands (their emphasis). They suggest that this helps to avoid reduced functioning resulting in 'either/or thinking', which threatens the potential for participation and contribution.

The ICF has its critics amongst disability scholars (see Oliver and Barnes 2012; Goodley 2011:20). But it has also somewhat accommodated criticisms by disability scholars of the medical model (Bond and Cabrero, 2007). For example, Shakespeare (2006:59- 62; 2013:221;2014a:80) points to difficulties operationalising it, but supports the ICF because it is ‘interactional’, making it more appropriate than the social model for theorising disability.

Thus, the ICF biopsychosocial model is considered consistent with the framework of critical disability theory because it balances contributions of personal responses to impairment and barriers imposed by the social environment (Hosking 2008:7). Hosking’s (2008:7) characterisation of one of the ways that disability is understood within critical disability is consistent with it:

> …. a complex interrelationship between impairment, individual response to impairment, and the social environment.

Approaches associated with critical disability theory are considered useful in challenging individual, medicalised approaches to disability in older age (McGrath *et al.* 2017).

Thus, interactional/biopsychosocial definitions and insights from a critical disability perspective, if incorporated into research and practice for people experiencing disability in older age, might help move beyond medical or individual approaches. However, interactional understandings of disability are not applied generally to understandings of disability as used in older age, something I turn to next.

2.3 Approaches to Disability in Older Age: Biomedical and Sociological

Medicalised approaches to defining disability are especially influential in the field of ageing (Verbrugge and Jette 1994; Oldman 2002; Estes, Biggs and Phillipson 2003; Bond and Cabrero 2007). However, they tell us little about the social construction of ageing in a broad socio-political context. But because of the dominance of biomedical explanations, I consider how they conceptualise impairment, disability, and the related idea of ‘frailty’. I also discuss the related concept of the ‘fourth age’ within sociological perspectives and discuss their relevance to this study.

2.3.1 Dominant Definitions – Biomedical

Gerontology emerged at a time when biomedicine was extremely influential; it views the ageing process as characterised by decline and decay (Estes, Biggs and Phillipson 2003).

Disability equated with Functional Impairment

While texts from disability studies begin from an assumption that there are important and conflicting interpretations surrounding disability (Titchkosky 2000), disability in older age is seen in biomedical literature as a straightforward ability/inability to perform certain actions, traditionally using terms like ‘functional impairment’, ‘level of ‘dependency’ or ‘frailty’ (Woodhouse *et al*.1988). The most commonly used measures are self-reports of difficulty with:

- ADLs: basic activities of daily living (such as mobility and self-care), and
- IADLs: instrumental activities of daily living (such as such as preparing meals, shopping, taking medication) performed to live independently (see Fried *et al.* 2001).

Some research recognises the need for a wider focus on environmental factors (Burden of Disease Network Project 2004) and critics point to the limitations inherent in its narrow approach (see Ryff and Singer 1998; Lloyd 2012).

Concepts of ‘Frailty’ and ‘Disability’

‘Frailty’ is a dominant theme in geriatric research (Grenier 2012:170). Kelley-Moore (2010:103) characterises frailty as a ‘physiological state entailing reduced stamina and strength’. But there are many definitions: some equate frailty with disability, comorbidity (having several conditions), advanced old age or with targeting of services such as long-term care (Fried *et al.* 2001). While there is no single definition, narrow physical/medical definitions predominate (Puts *et al.* 2005; Nicholson *et al*.2013). Fried and colleagues (2001) identify a greater likelihood of frailty amongst women and those with lower economic status, and lifecourse approaches link it with early life experiences (see Kuh 2007). There are no widely accepted criteria to identify ‘frail’ persons (Puts *et al.* 2009) and prevalence estimates differ due to different definitions (Manthorpe and Iliffe 2015).

One question relevant to this study is whether biomedical literature distinguishes between ‘frailty’ and ‘disability’. Van Campen (2011) suggests that most frail older persons experience moderate or severe disability. Fried and colleagues (2001)[6]

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[6] This is a much-cited 7-year follow-up study of over 5,000 community-dwelling older people in the U.S. aged over 65. Frailty status was assessed based on the presence of any three of the following characteristics: unintended weight loss, self-reported exhaustion, weakness (grip strength), slow walking speed and low activity. The definition of ‘disability’ used was self-reported disability in terms of difficulty in mobility tasks, IADLs or ADLs (Fried *et al* 2001:149).

consider that frailty is not synonymous with either comorbidity or disability, but that disability is one possible *outcome* of frailty (others being risk of falling, hospitalisation and death). Thus, frailty, disability and chronic diseases are distinct but overlapping concepts, and frailty can be a pathway to disability (Daniels *et al.* 2008). However, it is complex, as some people who are considered 'not frail' are disabled and vice versa[7].

A critique of the concept of frailty is emerging, especially from critical gerontology (Kelley-Moore 2010; Manthorpe and Iliffe 2015; Grenier, Lloyd and Phillipson 2017). For example, Kelley-Moore (2010:103) highlights frailty's social origins, arguing for a social constructionist perspective to describe disabling environments linked with diminished social expectations and social structures that exclude or isolate seniors. Gilleard and Higgs (2010b:477) distinguish 'frailty' 'conceptually and operationally' from 'disability,' with 'frailty' representing 'a residual state that remains when other narratives and other identities can no longer be asserted or enacted'.

As far as subjective accounts go, older people do not always identify either as 'disabled' (even when otherwise classified as such) (Langlois *et al* 1996; Verbrugge and Yang 2002; Darling and Heckert 2010), or as 'frail' (Kaufman 1994a; Kaufman and Becker 1996; Grenier 2006; Grenier 2006; Nicholson *et al.* 2013). The literature has not devoted much attention to psychological effects of the transition to frailty (Fillit and Butler 2002) or to gathering the experience of those deemed frail (Nicholson *et al.* 2013).

Biomedical Definitions and This Study

The foregoing suggests that there is overlap in empirical terms between the populations of older people who are 'frail', have comorbidity or physical disability, so in practical terms, participants in this study who are disabled might also be considered frail and/or have multiple conditions. Grenier (2012:170) suggests that the concept of frailty as researched in biomedical literature represents 'the period characterised by impairment and decline' corresponding to the 'fourth age' within sociology. I discuss the sociological concept of the 'fourth age' below, but before doing so consider briefly one sub-field within gerontology.

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[7] For example, someone with arthritis in their hands may not be able to eat unaided (this would be considered disability) but not be frail; someone else might be frail but able to live independently – thus would not be considered disabled.

2.3.2 Environmental Gerontology

There is one sub-field within gerontology - environmental gerontology - originating in a psychological perspective, which addresses the issue of disability definition. From this perspective older age is profoundly influenced by the physical environment (Wahl, Iwarsson and Oswald 2012). The concept of personal-environmental fit has been used to examine the role of environment modifications on disability related outcomes in older age (Wahl and Weisman 2003; Wahl *et al.* 2009). These approaches remain somewhat outside the mainstream of ageing theorising (Wahl, Iwarsson and Oswald 2012),[8] but they offer useful analyses of physical homes/neighbourhoods. I include references to studies in this tradition in my discussion of disabling environments in **Chapter 8**. However, while valuable, this perspective tends to address disability within the individual experiences and not to take in other facets including interaction with social systems on individuals and groups (Putnam 2002). For that reason, I do not discuss them further in this Chapter.

2.3.3 Dominant Understandings in Sociology - Third and Fourth Ages

Laslett distinguished between the third and fourth ages, writing in a context where the ‘third age’ was intended to counter age-based discrimination (Grenier and Phillipson 2014:57). Third age was a time when, freed from responsibilities, one might pursue goals and lead a creative, fulfilling life (Laslett [1989]1996). Older people were ‘demeaned’ by being described in terms ‘properly belonging to an afflicted and decrepit minority’ – the fourth age, an ‘age of decline’, an ‘era of final dependence, decrepitude and death’, a time when people are ‘passengers or encumbrances’ and when it is proper to withdraw from life (Laslett [1989] 1996:3,4;5;194). Laslett did not attach chronological ages to third/fourth ages. There have since been attempts to do so (see Baltes and Smith 2003), but debates have moved on and the distinction is ‘qualitative not chronological’ with onset of ‘serious infirmity’ marking the point of transition (Grenier 2012; Twigg 2004:64). It is not clear how the AwD group – people who already have impairment prior to becoming older – fit within these frames.

Critical gerontologists, such as Gilleard and Higgs (2013:368), suggest that the third age has evolved as a generationally defined ‘cultural field’ characterised by consumerism, cultural engagement, the pursuit of leisure and an engagement with

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[8] For example, Wahl, Iwarsson and Oswald (2012) note how they are not included in key handbooks on theories of ageing.

the technologies of self-care. Others highlight how third age discourse disregards inequalities or structural factors and critique its alignment with the stereotyping anti-ageing industries (see Arber and Evandrou 1993; Phillipson 2013).

The fourth age is often linked to frailty and conceptualised as the antonym for successful ageing (Nicholson *et al.* 2012). It is characterised by the combined effects of ageing, illness and disability which irreversibly change a customary way of life and calls into question one's sense of self (Lloyd *et al.* 2014). It refers to both an age or staged-based period, and a cultural construct – or 'imaginary' (Grenier, Lloyd and Phillipson 2017).

Its characterisation as a 'social imaginary' (a largely unstructured and inarticulate understanding of social situations) comes from Gilleard and Higgs (2010a:122,123) for whom it represents not so much a particular cohort or stage of life but a kind of terminal destination operating as an 'under-theorized residual social category,' a social or cultural black hole. 'Deep', 'real' or 'frail' old age', is their model for the fourth age, involving a fear of passing beyond 'the possibility of agency, human intimacy or social exchange' (Higgs and Gilleard 2015:19; Gilleard and Higgs 2010a:125). And, in being considered a state which cannot sustain individual agency or 'individual narratives' this is similar to how Gilleard and Higgs (2010b:477) characterise frailty also, as already discussed, above.

Thus, there are a number of issues with the concept of the fourth age. Characterising it solely by impairment, means that people are socially and culturally 'othered' from society and within groups of older people (Grenier 2012:174), and it solidifies negative evaluations of those who cannot lay claim to 'autonomy, social independence and a youthful outlook' (Irwin 1999: 695).

Alternative interpretations focus on the fourth age as retaining possibilities for expression, communication and agency (Grenier 2009; Grenier and Phillipson 2014; Lloyd *et al.* 2014) and for perseverance in maintaining a sense of self and dignity of identity involving physical, mental and emotional labour (Lloyd *et al.* 2014). In empirical terms, there are problems with trying to identify the features that characteristise the fourth age (see Lloyd *et al.* 2014; Pirhonen *et al*. 2016) and social sciences have focused limited attention on subjective assessments of late-life disability (Kelley-Moore *et al* 2006; Grenier 2007). Most gerontological attention has focused on issues of the third age (Grenier 2012:182).

‘Fourth Age’ and This Study

The sociological concept of the fourth age, while not defined in a scientific way, is considered a ‘broad notion’ associated with ‘the intersections of age and impairment’ (Grenier and Phillipson 2014:57). As such, the ‘fourth age’ is highly relevant to this study. However, I do not adopt the term due to the problems with its characterisation already outlined.

2.4 Discussion: Defining Disability in this Study

This review suggests that different models are associated with different understandings of the category ‘disability’, and of who is encompassed within it. For older disabled people, biomedical definitions of disability and frailty in purely functional terms dominate, while social and biopsychosocial definitions are more common within disability studies and within medical sociology. Furthermore, much of the life experience that this study is exploring likely corresponds to the sociological concept of entering or living through the ‘fourth age’, though I do not adopt the term.

Hagestad and Settersten (2017:143) suggest that the WHO relational or interactional approach to defining disability has value for older people by seeing it as a *relation* between individual capacities and environmental demand, avoiding dichotomous thinking. Biopsychosocial models, thus, open the possibility of seeing disability in older age as more than a personal problem and of examining how extrinsic factors (social, economic, cultural, political) contribute. Biopsychosocial approaches can encompass both the DwA and AwD groups and are useful in attempting to bridge the separate fields of ageing and disability within scholarship, policies and practice (Naidoo, Putnam, and Spindel 2012). This approach to definition is compatible with critical disability theoretical perspectives that have moved beyond binaries associated with the social model of disability, and it informs international approaches to censuses and surveys of disability prevalence. As such, biopsychosocial approaches are valuable for this study.

Thus, I understand ‘disability’ in a biopsychosocial or interactional sense – as the outcome of the interaction between individual and contextual factors. This is consistent with the definition in Article 1 of the UN Convention on the Rights of Persons with Disabilities:

> …. those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

When I use the term ‘impairment’, I intend to exclude social or other external factors while also being aware that impairment can be regarded as socially constructed (see Tremain 2002).

I argue for this approach not only for its analytic properties but also its potential political efficacy. Thus, moving from biomedical to biopsychosocial understandings of disability in older age would acknowledge socially constructed aspects of disability, supporting a shift in policy to a focus on environmental accommodations that would facilitate older people’s functioning (Minkler and Fadem 2002:233). It might also help focus on interconnections between the physical, social and contextual, including structural disadvantage.

For this study, one practical implication of the discussion in this Chapter is that since a ‘disability’ identity is less likely to occur when people age into disability, self-identification as ‘disabled’ could not be relied on in terms of recruitment of participants. Thus, I return to this issue in **Chapter 5.**

Ultimately, as regards definition, I agree with the emphasis that Townsend (1981b) placed on the *outcomes* of disability for older people in terms of activities, roles and relationships in society (as referred to in the Introduction to this study). Similarly, I agree with Wendell (1996:22) that ‘what matters most in identifying disability is identifying the difficulties people face in surviving and contributing to their societies’.

Concluding Remarks

The aim of this Chapter has been to show how different definitions of disability operate in the fields of disability and ageing, and to clarify what I mean by the term ‘disability’. I adopt a biopsychosocial or interactional approach to definition – where disability arises from the interaction of personal and contextual factors. The discussion here forms a backdrop to the discussion of theoretical approaches to disability and ageing in the next Chapter.

CHAPTER 3: LITERATURE AND EMPIRICAL STUDIES: AGEING, DISABILITY AND LIFECOURSE

3.1 Introduction

This Chapter addresses one of the paradoxes I discussed in the Introduction to this study. Namely, that despite the fact that disabled people will age, and most who are ageing will experience disability (barring premature death), there are only separate theories on ageing and on disability and that this, 'impacts on our ability to conceptualise relationships between the two' (Murphy *et al.* 2007:48-9).

This Chapter has two parts, both intended to provide a reference point for the Chapters that follow. **Part 1** has three subsections that examine scholarship on (1) ageing, (2) disability, and (3) the lifecourse. **Part 2** reviews empirical studies with people experiencing disability for the first time with ageing (DwA) and those ageing with disability (AwD).

My review suggests that sociological understandings, especially of the so called fourth age (when impairment is more prevalent), are not well advanced, and that the subjective experiences and lifecourse transitions of those considered to be living in the fourth age are not well understood.

Comparing key theoretical perspectives on disability and on ageing suggests that critical studies (encompassing a range of perspectives) are now significant in both fields. But, while scholars often use similar paradigms to explore ageing and disability, the two fields largely progress on separate, if parallel, tracks. My review also confirms that scholars writing within gerontology and disability studies both recognise the need for more exploration of subjective experiences associated with disability in later life. Within existing literature, the AwD experience is particularly under-explored.

A key implication is that insights from social models of disability (and also reflected in medical sociology approaches) – that disability is not *just* a personal, individual issue and that it is (in part at least) socially created – has yet to be applied to any extent to the experience of disability in older age.

PART 1 – Theorising

3.2 Scholarship on Ageing: Social Theories

In this, the first of three subsections in Part 1 of this Chapter, I outline key social theories of ageing and focus on critical gerontology, which informs this study. As I showed in the Introduction to this study and in **Chapter 2**, biomedical approaches dominate the field of ageing, including the explanatory framework for disablement in older age. Existing literature places a large emphasis on identifying objective conditions of frailty (Grenier 2012) and less on subjective experiences of being older and disabled or on social causes of disablement (see Estes, Biggs and Phillipson 2003; Kelley-Moore *et al.* 2006; Nicholson *et al.* 2012). Despite a ‘huge industry’ addressing impacts of ageing populations, social science approaches are dominated by issues to do with the third age (that is, younger-older people or non-impaired older people) (Grenier 2012; Phillipson 2013:128). Thus, sociological understandings of late older age are considered to be at an early stage of development.

Current prominent perspectives in social gerontology theorising are social constructionism, feminist theories and critical perspectives (Bengtson, Putney and, Johnson 2005). My review focuses mainly on critical perspectives as they are most influential currently and they are of most relevance to this study. However, I first introduce two early theories – disengagement and activity theories – as these were key influences on subsequent gerontological research (Putnam 2002; Boudiny 2013) and continue to resonate with dominant socio-cultural discourses on ageing.

3.2.1 Early Theories: Disengagement Theory, Activity Theory and its successors

The first of these early theories that still resonates is **Disengagement theory**. It viewed older age as an inevitable period of withdrawal from roles and relationships in anticipation of death (Cumming and Henry 1961). Disengagement was viewed as natural, desirable and universal across cultures (see Estes, Biggs and Phillipson 2003). It attracted much criticism, including for its lack of concern with structural issues (see Walker 2006; Baars *et al.* 2006). Disengagement theory is seen as empirically wrong in the degree of its negativity (Walker 2002). However, themes of loss articulated within disengagement theory continue in decline ideologies of ageing that are still influential (see Baars 2010; Gullette 2004).

The second - **Activity theory** (Havighurst and Albrecht 1953) - aimed at ‘denying the onset of old age and…replacing those relationships, activities and roles of middle age…with new ones’ (Walker 2002:122). It treated retirement and widowhood as the key role transitions (or losses) of later life, which meant that satisfaction had to be found in substituted roles (Ferraro 2001:314). Activity theory stimulated the development of several social psychological theories of ageing including successful ageing (Rowe and Kahn 1987; Baltes and Baltes 1990a).

The empirical link made in activity theory between activity and wellbeing in older age is considered valid today (Walker 2002). Thus, activity theory is associated with concepts that influence contemporary socio-cultural discourses and policy-making trends encompassing various terms - positive, successful, active, productive, or healthy ageing and also including third-age discourses. ‘Active ageing’ is the term used in the policy field, which aims to delay disability and chronic illness by encouraging healthy lifestyles (World Health Organization 2002a:9;13). Debates over these approaches go to the heart of ageing studies (Estes, Biggs and Phillipson 2003:67) and are still part of debates in critical gerontology (see below).

Rowe and Kahn (1997:433) defined ‘successful ageing’ as encompassing avoidance of disease and disability, maintenance of high physical and cognitive function, and sustained engagement in social and productive activities. Many risk-factors were considered modifiable by individuals. Widely researched, this definition of successful ageing continues to be dominant (Bowling and Dieppe 2005). Baltes and Baltes (1990b) present a psychological model, suggesting that older people do the best with the functioning they have and maintain it with adaptation strategies[9].

While these approaches sought to counteract the old ‘decline and loss paradigm’, a range of scholars critique them (see Katz and Calasanti 2015). Of most relevance to this study are critiques challenging the equating of ‘successful ageing’ with good health and by extension disability and/or poor health with failure (see Holstein and Minkler 2003, 2007; Priestley 2003a; Phillipson 2013). These often come from critical gerontology.

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[9] This involves a model of selective optimisation with compensation (or SOC) – which suggests that older people achieve satisfaction by using strategies to age well when faced with loss.

It is not known if disabled people consider these concepts relevant to them (Phillipson, 2015:90), but some research on this is emerging (see Larsson 2013; Romo *et al*. 2013; Stowe and Cooney 2015; McGrath *et al.* 2016). One study (Romo *et al.* 2013) found that participants who experienced impairment often felt that they *had* aged successfully.

McGrath *et al*. (2016) sum up the impact of these kinds of positive aging discourses: while they initially sought to counteract negative stereotypes of 'oldness', the way they have evolved may inadvertently reinforce stigmatising views of disability in later life by framing disability as a matter of failed personal responsibility.

3.2.2 Ageing as a Social Construction – Introducing Critical Gerontology

Political economy, which subsequently became critical gerontology, assumed major significance from the 1980s (Philipson and Baars 2007). As already referred to, critical gerontology involves a value-committed approach focused on changing the social construction of ageing. A critical approach to theory and policy goes beyond 'everyday appearances and the unreflective acceptance of established positions' and focuses both on structural inequalities and personal experience of ageing (Estes, Biggs and Phillipson 2003:3). It is associated not only with critiques of sociopolitical environments but also of mainstream gerontology (Holstein and Minkler 2007:16-7; Ray 2008).

Critical gerontology is constituted by political economy and moral economy approaches (Paris 2016). The **political economy** approach drew on Marxist insights to interpret the relationship between ageing and economic structures (see Powell and Hendricks 2009). In the U.S., it is associated with Estes (1979) and others; in the U.K., with Townsend (1981a), Walker (1981a), Phillipson (1982) and others. Townsend (1981a) highlighted the 'structured dependency' of later life as a product of forced exclusion from labour markets, passive forms of community care, and poverty.

Phillipson (2013) suggests that political economy theorists now need to engage more with the social dimensions of health and related changes affecting people in their 70s, 80s and beyond. And Kelley-Moore (2010) suggests that gerontologists could learn about the social construction of disability from disability scholars.

The **moral economy (including cultural and humanistic) perspective** within critical gerontology has the most relevance to this study because of its focus on subjective meaning-making processes of older people. It is associated with an appreciation of the interplay between culture, structure and agency and focuses on questions of meaning and experience (Estes, Biggs and Phillipson 2003). The focus is on subjectively constructed experience within a wider context, and on how cultural understandings of age and ageing affect meaning, interpretations, experiences and identities (Cole, Van Tassel and Kastenbaum 1992; Moody 1993; Gullette 1997; Andersson 2002; Ray 2008; Grenier 2012; Minkler and Estes 1999; Edmondson 2015).

There is increasingly a tendency for the term ‘cultural gerontology’ to be used to characterise the broad range of areas within this perspective. Twigg and Martin (2015) suggest that the most characteristic feature of cultural gerontology is a concern with meaning. Another trend is for the two strands of critical gerontology to come together or to combine insights on structured conditions with lived experience (Grenier 2012).

As indicated in the Introduction, while this study aligns especially with the moral economy or cultural perspective, political economy perspectives can also be said to have influenced its approach – including its exploration of assumptions about ageing and disability that are implicit in policies and institutional practices.

3.2.3 Moral Economy (or Cultural) Gerontology

This is a broad area of scholarship, from which I focus on three areas that are relevant to the arguments of this study. I focus on **cultural representations**, which are relevant to how identities of older people are negotiated, as well as how they (and others) interpret their age and life-stage, and impairment onset/worsening. Second, I focus on how the issue of the **body** is approached within theorising. Finally, I focus on how **meaning in life** is approached, as a key argument of this study is that this becomes a vitally important issue for disabled older people.

Cultural Representations

In general, critiques of cultural representations of ageing have two separate targets that correspond with the two propositions represented in the early theories discussed above.

First, there is a critique of the cultural reduction of old age to a period characterised by decline and inevitable deterioration into a state of frailty and dependency, reducing the identity resources of older people to these limited representations and roles (see Gullette 1997, 2004, 2010; Cruikshank 2003,2008). Critiques highlight how these narratives fail to acknowledge diversity and can result in overlooking possibilities for growth and renewal (Cruikshank 2008: 150). Some scholars critique the ‘decline’ perspective for reducing the potential for meaning in later life. As Laceulle (2016) argues, ‘decline’ discourses fail to recognise people’s aspirations for self-realisation.

A second critique focuses on cultural perceptions associated with ‘successful’ ageing (and cognate ideals, as outlined above) while sometimes also acknowledging the value of these approaches in challenging some of the myths of ageing. Critiques (see Katz, 2005; Twigg, 2004; Phillipson 2013) contest the implicit suggestion that to age ‘successfully’, one needs to try and stay young and avert decline as long as possible, or with the exaltation of the freedom and opportunities of the third age. Thus, these critiques often highlight how positive images of ageing risk further stigmatising older people who do not fit the ‘active’ norm promoted especially by commerce (Irwin 1999). For example, the oldest old – those most likely to have impairments or be disabled – may be marginalised by the related cultural focus on a consumerist life-style, leisure and activity associated with positive discourses (see Cohen 1988; Morell 2003). A similar critique is made in respect of the AwD group (Minkler and Fadem 2002:229).

Gilleard and Higgs (2013:372) sum up these critiques with a vivid image, suggesting that ‘the brighter the lights of the third age, the darker the shadows they cast over the underbelly of aging – fourth age’. Furthermore, with a strong emphasis on remaining ‘youthful’, this approach also overlooks the fact that older age may have a value of its own (Laceulle 2016:99-101).

Instead, Grenier, Lloyd and Phillipson (2017) argue for responses to ageing that develop from acknowledgement of fragility and limitations. Others call for the development of alternative narratives that focus on self-realisation or self-development for all older people, not just those in the so-called third-age (see Cruikshank 2003:23; Laceulle and Baars 2014; Laceulle 2016).

Some scholars identify fear as a factor in keeping in place the dichotomous thinking about older age. For example, for Nicholson (2009:35) the ‘separating out’ of older ‘frail’ people may be an ‘organisational defence against the difficulties and anxieties of dependency and mortality’. Similarly, West and Glynos (2014) argue that the more third age independence/resistance are socio-culturally valorised, the stronger is dependency repudiated and projected onto others. These arguments resemble arguments from disability studies about the othering of disabled people, something I return to below.

Also, a small number of gerontologists now use concepts from disability studies to highlight harmful aspects of ‘successful’ ageing and related concepts and to focus on social factors of disablement. For example, for Jönson and Larsson (2009:75), normalising people by comparison with a prolonged mid-life constitutes a form of ‘ableism’[10]. Similarly, Gibbons (2016) characterises the successful ageing approach as ableist (as well as ageist) constituting what she characterises as compulsory-youthfulness, involving ableism and ageism in reinforcing youthfulness and able-bodiedness as ideals (by reference to McReur’s concept of compulsory able-bodiedness, see below). McGrath and colleagues (2017) draw on critical disability theory to suggest a focus on interdependence over traditional notions of independence, and to question assumptions pertaining to ‘normalcy.’ They argue for a broader interpretation of what constitutes normal or abnormal. Yet, as I already argued in the Introduction to this study, most critical approaches focus *either* on disability or ageing.

The Body and Identity

Influenced by postmodern and poststructuralist perspectives, scholarship on the body and identity sometimes suggests that identities of older people are less constrained and more open to consumerist choices, including the possibility of transcending the ageing body (see Featherstone 1991). For Featherstone and Hepworth (1991) a culturally imposed ‘mask of ageing’ hides a more youthful ageless self. But feminist critics dispute attempts to draw a radical separation between the body and the sense of self (Twigg 2004).

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[10] Campbell 2001: 44: ‘**Ableism** is a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human.’ Miller *et al*. 2004:9: **Disablism** is ‘discriminatory, oppressive or exclusionary behaviour arising from the belief that disabled people are inferior to others.’

Twigg (2004, 2006) brings an understanding of both biology and culture to gerontology discussing bathing and caring for older bodies. For Twigg (2004:59,71), feminist scholarship has been slow to engage with issues of the ageing body and has been slower to consider the ‘fourth age of frailty and dependence’. She argues for more understanding of the role of the body in deep older age. Hockey and James (2003:106;116) argue that the ‘chronologised body’ continues to ‘be a source of constraints,’ as consumerist practices paradoxically intensify the focus on the determining role that biology and chronological age have in conceptualisations of ageing. Thus, the role of the body as a marker of social identity is significant, which is relevant to the findings I present in **Chapters 8** and **9.**

Social constructionist approaches show how identities are not reducible to ‘natural’ or ‘biological’ factors (see Shilling 2012). Some sociological approaches focus on social attitudes to the appearance of ageing within post-modern culture (see Gullette 2004). But Holstein and Minkler (2007:17-18) suggest that traditional approaches within social gerontology fail to notice the real bodies of old people. Thus, strong social constructionist approaches do not fully engage with the ageing body (Higgs and Rees-Jones 2009). These approaches do not represent the position I adopt in this study. I take a position consistent with Cruikshank’s (2008:151) argument that both bodily experiences *and* cultural interpretations are relevant. I will come back to these arguments in **Chapter 8** when discussing my findings.

To the extent that post-modern approaches focus less on striving to be young than claiming positive old age identities (Featherstone and Hepworth 1995; Gibson 2000), there are parallels with the kind of positive disability identities claimed by younger disabled adults (Priestley 2003b:62; see Lenny 1993). And while the disciplines of feminist disability studies and feminist gerontology have remained disparate fields (Gibbons 2016), Morell (2003) represents an exception. She relies on disability scholar, Wendell’s (1996) notion of the ‘rejected body[11]’ to argue that important needs of older people will be neglected while the rejected body is ‘feared and ignored’. Thus, scholarship in gerontology echoes attempts to reintroduce the body and impairment into discussions of disability theory.

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[11] Wendell (1996:85) characterises the ‘rejected body’ as the body associated with weakness, disability and death as feared, despised or rejected in a society/culture.

Meaning in Life

Moody and Sassar (2012) and Holstein (2015) are amongst those scholars highlighting meaning as an important dimension of later life. Yet, Edmondson (2015:1,3) suggests that meaning is seldom discussed directly in respect of later life, arguing that exclusionary practices frame meaning for older people (and their meaning to societies) as trivial, related to a societal view that worthwhile activities are performed largely by those in paid work.

Laceulle and Baars (2014) suggest that stereotyping cultural narratives of ageing (decline or age-defying) deprive older people of meaningful frames of reference. As discussed in the Introduction to this study, Baars (2017) attributes the lack of perspectives that explore ageing's potential for meaning (beyond 'decline' or 'age-defying' narratives) with a late modern failure to identify with the fact that vulnerabilities and limitations *and* creativity and fulfilment are all part of later life. The lack of emphasis on meaning in older age is perhaps surprising given that the need to meet self-realisation or actualisation needs is likely to grow with age (Thompson 1992; Bauer and Park 2010; Dannefer and Lin 2014). This is because the meaning we give to our lives is affected by illness/impairment that changes our relationship with our bodies and with family and friends (Holstein 2015).

Meaningful orientations prevent the world from being experienced as a 'chaotically unconnected succession of impressions' (Baars and Phillipson 2014:11), but relatively little research has been done on what it means to lead a meaningful life (Derkx 2013; Edmondson 2015). Definitions of meaning in life often identify a number of domains or needs – and I will return to these in **Chapter 9**.

Some studies explore meaning with older people generally (Thompson 1992) or with those in the third age (Weiss and Bass 2002), but there is little/no exploration in the literature specifically of how older people who experience disability, or are considered to be in the 'fourth-age,' find meaning in life. Referencing how the transition to impairment or the fourth age is under-recognised in scholarship, Grenier (2012:175) argues for more consideration of the fourth age as a process of 'making meaning of continuity and change.'

I will return to this issue of meaning in life in **Chapter 9**, where I discuss the key argument of this study, that disabled elders respond to losses by trying to remake lives in ways they perceive as meaningful.

3.2.4 Critical Gerontology – Contributions from Older People?

Few gerontologists are old (Biggs 2004) and they rarely write from the perspective of an older person, let alone an older disabled person. Feminist literature around identity is often passionate and subjective about the third age, but distant about the fourth age: ‘about them – the old - not us’ (Twigg 2004:64).

Hagestad and Settersten (2017:136,143) argue that ‘ageism and stigma’ are perpetuated by gerontologists who carry on two discourses - lauding active ageing in public and confessing to limitations and precariousness in private with few making ‘private stories public’. But, following his 85th birthday, Cohen (2017:117) did so, saying that he did not anticipate the disengagement that death and geographical removal of family/friends would bring, or the impact of progressive hearing loss on relationships. He describes himself as having been ‘in quiet denial’.

While it may be beginning to change (see Ray 2008), this lack of contributions by theorists who identify as ‘older’ distinguishes social gerontology from disability studies, which have always been more aligned with disability activism.

3.3 Scholarship on Disability – Medical Sociology and Disability Studies

In this section, I turn to scholarship on disability. When discussing models of disability in **Chapter 2**, I referred to two fields that seek to define disability - medical sociology of chronic illness/disability (associated with biopsychosocial models), and disability studies (associated especially with social models). Here I consider theories from medical sociology, and then consider theories within disability studies. In both cases I consider how/whether they address ageing.

3.3.1 Medical Sociology

Medical sociology of chronic illness and disability is associated especially with Bury (1982; 1997), Williams (2000) and Charmaz (1995). Bury’s (1997) starting point is that most disabled people experience chronic illness. Although there have been attempts within disability studies to draw a line between chronic illness and disability (see Barnes and Mercer 1996),[12] the importance of chronic illness is recognised in disability studies too (see Wendell 1996, 2013; Crow 1996; Thomas 2007; Shakespeare 2014a; Bê 2016). Bury (1997) understands disability as occurring both in bodies *and* due to social disadvantage. From this perspective, reducing barriers to participation is important, but social model arguments that disability is social oppression are ‘over-socialised’ (Bury 1997:138)[13].

A key aspect of theorising addresses onset of chronic illness or impairment, seen to interrupt an individual’s previous lifecourse assumptions and narratives, forcing renegotiation of biographical identities; this is called biographical disruption[14] (Bury 1982:169-70). This is in the context of modern cultures premised on a general expectation of long life and of health (Bury 1997:124).

The relationship between age and chronic illness is under-theorised from this perspective (Higgs and Rees-Jones 2009:2-3). And the perspective of the AwD group is largely missing (Williams 2000; Larsson and Jeppsson-Grassman 2012). However, Williams (2000) suggested that age, timing and context might be important factors - chronic illness might be a biographically *anticipated* event in later life.

Some studies seem to confirm this approach, suggesting that chronic illness might ‘cease to be ‘out of place’ or ‘special’ in older age’ (Pound, Gompertz and Ebrahim 1998). On the other hand, other studies (see Sanders, Donovan and Dieppe 2002; Meijering *et al.* 2016[15]) suggest that biographical disruption can be experienced at older ages as well as younger, and Larsson and Jeppsson-Grassman (2012) suggest it can apply to the AwD group. This points to the need for more research.

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[12] Shakespeare (2006) associates this with the fact that a core group of activists/theorists associated with emergence of the U.K social model had spinal injury. He argues that the social model approach lends itself to distancing from chronic illness, because, for people with static conditions that do not degenerate or cause complications, disability may be considered as entirely socially created; however, for those with pain, discomfort or degenerative conditions, it is harder to ignore negative aspects of impairment.

[13] Critiques from within disability studies suggest that this perspective insufficiently locates disability in wider economic or political structures (Thomas 2007), and focuses on ‘coping’ or ‘adjusting’ rather than rights (Bê 2016). But others (see Shakespeare 2006,2014b) explicitly align their understandings with that of Bury.

[14] This was based on Giddens’ notion of a ‘critical situation’ (Giddens 1979 cited in Bury 1982).

[15] The study by Meijering *et al.* (2016) focuses on therapeutic engagement with the rural landscape; thus they discuss biographical disruption/flow as bio-geo-graphical disruption/flow.

Despite similar concerns, medical sociology, social gerontology and (for the most part) disability studies proceed separately (see Thomas 2007; Higgs and Rees-Jones 2009). But I suggest that the concept of biographical disruption is useful in interpreting the meanings that older people make of impairment onset/worsening, and I employ the concept, especially, in **Chapters 7** and **8**. It is useful because it resists both post-modernist challenges to a biographically embodied approach, and social constructionist approaches that write the body out of the picture (see next section).

3.3.2 Introducing Disability Studies

I turn now to consider disability studies. Overall, within disability theorising, older people have largely been left out of debates and the focus has been on disabled children and adults (Priestley 2006; Thomas and Milligan 2018). Thus, both the AwD group and the DwA group are largely left out.

There are four foundational approaches to disability theorising (see Priestley 1998; 2003a; Gabel and Peters 2004; Goodley 2011). The term ‘critical disability studies’ describes ‘the state of the field’ in disability studies now (Goodley 2013:631-32). I focus in this section on critical disability studies, but refer briefly first to materialism, one of the foundational approaches, for its influence on subsequent approaches. It also has parallels in theorising on ageing.

Materialism is the foundational principle of the U.K. social model (see Finkelstein 1981,1998; Oliver 1990,1996; Barnes 1997,1998) in which capitalism was perceived to have caused the oppression of disabled people (Oliver 1990,1996). This perspective focuses on material exclusion and social marginalisation, excluding accounts of the body. Parallels exist with the political economy perspective on ageing, which linked the structural dependency of older age and social policy developments during the 20th century (see Townsend 1981a). However, the form it took within disability studies remained a heavily materialist-oriented approach and involved over a decade of ‘dogmatic policing of disciplinary, researcher, theoretical and practice boundaries’ (Meekosha and Shuttleworth 2009:55). But materialism could explain only so much for researchers who followed (Goodley 2013).

Nevertheless, as I argued in **Chapter 2,** even its critics acknowledge the political usefulness of the social model that was developed within the materialist perspective. The social model has ‘almost iconic status’ and disability scholars are almost always in dialogue with it (Thomas 2004:573). This is because it turned traditional views of disability upside down (Shakespeare 2006:31; 2013), something that is in marked contrast to the continued domination of biomedical approaches within ageing studies.

3.3.3 Cultural/Critical Disability Studies

What is now termed cultural or critical disability studies arose from contributions by humanities and cultural studies scholars (Shakespeare 2014a; Meekosha and Shuttleworth 2009:50). Goodley’s (2013:634) review of this literature includes a range of perspectives within the term ‘critical’, explaining that they all emphasise ‘cultural, discursive and relational undergirdings’ of the disability experience. I discuss here **cultural representation and relational issues**, **bodies**, and **identity** for their relevance to the arguments of this study – and I look at if/how ageing is considered within these approaches.

Cultural Representations and Relational Issues

Reacting against the foundational approach to disability which stressed material and economic bases for discrimination, scholars who followed argued that cultural representations resulted in prejudice experienced in everyday interactions (Riddell and Watson 2003; Watson 2003).

These approaches emphasised cultural production and reproduction of disability through representation and stigmatisation of disabled people as ‘other’ due to negative imagery in media and literature and through disabling attitudes and values (Shakespeare 1994; O’Donnell 2007). For example, Shakespeare (1994) argued that prejudice based on projected fears reinforced a subordinate role for disabled people. For Snyder and Mitchell (2006:19), representations of disability and impairment are manufactured by charities, science and popular culture in ways that *dis*-locate disabled people.

A focus on the relational issues that cause exclusion or oppression is traced to Hunt ([1966]1998), Morris (1991) and others who suggested that, in daily-interactions with others, disabled people become aware of their difference – and that this is central to the segregation and oppression they experience. Watson (2003) highlighted how disabling social relations (like being ignored or denied agency or experiencing others' embarrassment) make disablism part of disabled people's everyday lives. I will consider my findings in light of this in **Chapter 8.**

Disability scholars argue that non-disabled people project fear of difficult aspects of existence - mortality, frailty and vulnerability - onto disabled people (Morris 1991; Hevey 1991; Shakespeare 1994). Scholars identify issues common to disabled people and older people. For example, in a seminal essay, Hunt ([1966]1998) suggested that disabled people – and those who are sick or old[16] – are a reminder of what is most feared in life, including death. Morris (1991:85) argued that isolation and oppression of disabled people and ill or old people come about through fear and denial of 'frailty, vulnerability, mortality and *arbitrariness* of human experience'. For Priestley (2002,2003,2006), cultural distancing of older and disabled people is reinforced by modernist discourses of independence, productivity and youth that devalue older and disabled people as non-adult dependents. Thus, Morris, Priestley and others point to similarities in the cultural construction of disability and older age; some scholars in gerontology do likewise (see Irwin, 1999; Twigg 2004).

In short, similarities in underlying fears lead to cultural distancing from both older people and disabled people (Irwin 1999), and both disabled and older people are denied full personhood (Luborsky 1994). Perceived limitations of the bodies of members of 'dependent social categories,' preclude the granting of full personhood, in contrast to the positive value placed on independent adulthood (Hockey and James 1993:102).

Bodies

Again, reacting to foundational approaches, feminist scholars, especially, critiqued the omission of the body from the social model of disability (see Morris 1991; Crow 1996; Corker 1999; Corker and French 1999; Shakespeare and Watson 2002). Famously, Wendell (1996:66;85) encouraged identification with the 'rejected body' (associated with weakness, disability and death and feared or rejected in society/culture), arguing that self-acceptance and liberation for disabled people

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[16] Hunt's perspective is that of a younger person; when he talks about the 'old' or 'the aged' he seems to mean those who are ill or disabled as in 'so they [able-bodied people] are inclined to avoid those who are sick or old, shying away from the disturbing reminders of unwelcome reality' ([1996]1998:16).

requires accommodating a range of physical conditions. But the embodiment focus of much critical/cultural theorising is on meanings that originate in texts (see Titchkosky 2007) or on shifting from the body as the object of scrutiny to the institutional or medical gaze (Snyder and Mitchell 2001:370-74). Another approach - phenomenological - characterised impairment as both an experience and a discursive construction (Hughes and Paterson 1997:329).

Both Twigg (2004), considering ageing bodies, and Hughes and Paterson (1997), considering disabled bodies, argue that there is a danger that macro-level approaches have abandoned the topic of the body over to medicine.

Identity and Intersectionality

Membership of a shared disabled collective is generally viewed positively, its basis sought in shared resistance to oppression (Shakespeare 2014a). But approaches to identity linked to activism are challenged. Shakespeare (2014a) argues that only a minority of disabled people engage in disability activism, and that disability experience is heterogeneous (Bickenbach *et al*. 1999; Shakespeare 2014a). Post-modernist thinking also makes the construction of a shared political vision more challenging (Riddell and Watson 2003).

An affirmation model challenged the idea of impairment as a problem, emphasising instead benefits like escaping role restrictions and social expectations and having empathy with others (Swain and French 2000). Shakespeare (2014a) acknowledges the need for approaches that include positive aspects of life with impairment and possibilities for adaptation and flourishing, but also argues that for most disabled people impairment *is* a difficulty.

An outcome of feminism and postmodern thought has been a problematisation of singular conceptions of disability (Meekosha and Shuttleworth 2009) and multidimensionality is a feature of critical disability theory (Hosking 2008). Examples include Campbell’s (2001;2009) intersectional analysis that shifts attention away from the problems of disablism (‘the Other’) to the problems of ableism (‘the same’ or ‘the dominant’). Davis (2013b:12) challenges ideas of normalcy – identifying the ‘problem’ not in the disabled person but in how normalcy is constructed and suggesting the need to reverse the ‘hegemony of the normal’ and institute alternative ways of thinking about the ‘abnormal’.

Another area is the merging of queer and disability studies, an example being the development of crip theory (McRuer 2006). McRuer (2006) builds on the idea of compulsory heterosexuality (from Adrienne Rich) to develop the concept of compulsory-ablebodiedness – challenging the idea of being able-bodied as an ideal. However, disability scholars have not challenged ableism or compulsory-ablebodiedness in the way that successful ageing discourses have evolved (see Gibbons 2016).

As I suggested in the Introduction, Shakespeare (2014a) both validates (for enrichment of thinking) and critiques these cultural approaches for over-concern with texts and discourses and suggests that they are limited because they do not engage sufficiently with disabled people's lives or on how they feel about their embodiment.

Critical disability theory also questions, among other things, concepts of personal independence and interdependence, suggesting that all adults exist in varying states of dependence and independence (Shakespeare 2000a,b; Hosking 2008). These arguments are sometimes seen as conflicting with approaches of feminist care researchers (Kelly 2016), and the two fields proceed along largely separate lines with little sense that they are exploring and explaining different aspects of the same phenomenon (Fine and Glendinning 2005).

Even though I have highlighted here how scholars in disability and ageing identify some similar issues, critical disability studies and critical ageing studies remain separate (Grenier, Griffin and McGrath 2016), and the main focus in disability studies is on issues concerning young people and adults. But, as I argued in the Introduction, there are some indications that this is changing. For example, Davis (2013a:272) highlights how increased disability due to population ageing means that it is necessary to discover how older people will define disability. And Garland-Thomson (2016) argues for a more universal engagement with disability issues because many or most people will experience disability at some point in the course of their lives. There is also an emerging focus on whether dementia constitutes disability (Thomas and Milligan 2018).

3.3.4 Disability Studies – Theorising by Disabled People

As mentioned, one thing that distinguishes disability studies from social gerontology is the prevalence of disabled people contributing to theorising (including Hunt, Finkelstein, Oliver, Corker, French, Morris, Shakespeare, Wendell, Garland-Thomson) and often to activism also. However, the perspective or voice of older disabled people - even the AwD group - is not well represented. Writers, like Morris (1991) and Crow (1996), recognise the experience of late-life disability, but from the perspective of a younger disabled person. There are, however, some empirical studies that explore the AwD experience (for example, Zarb and Oliver 1993), something that I discuss in the second part of this Chapter. But next, I discuss lifecourse studies in the third and final section of Part 1 of this Chapter.

3.4 Scholarship on the Lifecourse

I turn now to discuss a third (and final) field of scholarship that I consider in this Chapter. As I said in the Introduction, this study is grounded in a social constructionist lifecourse perspective and I discuss this approach, below. One aim here is to distinguish the approach I am taking and what it means for some of the terms I use, because terms can be used with different understandings in a range of lifecourse approaches. The lifecourse perspective is the most widely cited theoretical framework in social gerontology today (Bengtson, Putney and Johnson 2005:13). But there are different approaches. Here I introduce the lifecourse perspective within sociology and refer to how it has been applied to the study of older age and disability. I look at approaches to lifecourse studies within social gerontology and public policy and I discuss the constructionist lifecourse perspective that informs this study.

3.4.1 'The Lifecourse perspective'

Associated especially with Elder (1975; 1994), the lifecourse perspective is described as a 'theoretical orientation' that guides questions, conceptual development and research design and is associated with five well-recognised general principles[17] (Elder, Kirkpatrick Johnson and Crosnoe 2003:10-13). From this perspective, the lifecourse consists of 'age-graded patterns' 'embedded in social institutions and history' (Elder, Kirkpatrick Johnson and Crosnoe 2003:4). Researchers attempt to explain how ageing is shaped by social contexts, cultural meanings and social structural location (amongst other things) (Bengtson, Putney and Johnson 2005:14).

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[17] Principles of life-span development, agency, time and place, timing and linked lives

The emergence of the lifecourse perspective is associated with modernisation processes that led to a gradual differentiation in age groups (Hunt 2005:18) and it often presupposes that an institutional pattern shapes lives (Kohli 1986; 2007;256). Thus, the lifecourse is often seen as tripartite (preparation for work, working, and retirement) (Kohli 1986;2007;256; Heinz 2004:194).

Scholars have examined various types of transitions, often drawing on trends and comparisons of groups and cohorts. Transitions can be seen as anchor points from which to observe social change (such as family type) (see Hareven1978). Thus, the study of transitions often involves exploring normative structural change (Muraco and Fredriksen-Goldsen 2016:125). Studies often explore how earlier experiences/resources condition later actions and opportunities (Kohli 2007).

Within social gerontology, the lifecourse perspective is associated with linking features of early life to outcomes in later life (for individuals or populations) and with a shift from understanding ageing as a ‘process of organismically governed change’ towards a recognition of the important role of context and experience over time (Dannefer and Settersten 2010:3-7). Late-life impairment (and its prevention) is often placed in the context of earlier stages of life (Walker 2014:9) rather than focusing on specific aspects of later life (Grenier 2012:29). Themes of the body and the ageing body are often absent (Jeppsson-Grassman 2013:19).

Applied to the issue of disability, the lifecourse perspective provides insights into institutions and assumptions that shape the experience of both disabled people and non-disabled people (Irwin 2001). A critical understanding of disability can challenge both lifecourse institutions (like policies for employment or pensions) and the cultural rules that define what a ‘normal’ life means (Priestley 2001; 2003a). Also, notwithstanding a postmodern emphasis on choice of identities and unlimited possibilities for reflexive biography, these are limited by resources and barriers that disabled people face (Priestly 2003a).

The lifecourse perspective is recognised as potentially useful in relation to bridging research on ageing and disability (Priestley 2001; Naidoo, Putnam and Spindel 2012). Priestley (2001) argues for more research from this perspective on the ‘intersecting pathways’ of the AwD and DwA groups. However, the experiences that I focus on in this study – disablement processes occurring in later life often in ways that are not marked institutionally - tend not to be much explored as transitions in this literature (Grenier 2012).

This perspective – which I will refer to as 'the lifecourse perspective' - encompass a vast scholarship. There are differing understandings of, and approaches to, lifecourse studies. There are also humanistic or interpretive approaches (see Holstein and Gubrium 2000; Hockey and James 2003), which can be used to explore socio-cultural constructs of age, individuals' relationships with policies and practices, and negotiated identities (Grenier 2012:35). This is the approach, I take (see below). First, it is necessary also to distinguish the 'lifecourse perspective' from lifecourse and lifecycle approaches within social policy and social gerontology, which I discuss next.

3.4.2 Social Policy and Gerontology - Approaches to Lifecourse Studies

Critical gerontology and lifecourse approaches both aim to understand the interplay of structures, history, context and experience (Grenier 2012:35). But studies from the lifecourse perspective (see Elder 1975; Hareven 1978; Hareven and Adams 1982) are separate from those from within social gerontology that focus on the transitions experienced in late life (see; Ferraro 1984 (widowhood); Chambers 2000 (widowhood); Phillipson 2002 (retirement)).

While much work in social gerontology claims to ground analysis in the lifecourse, what is often meant, and this is also reflected in social policies, is the view that ageing must be conceptualised as a process across the span of a lifetime (Grenier 2012). This approach (contextualising an individual's experiences in the context of their life or taking a holistic view of life) differs from 'the lifecourse perspective' associated with Elder and others (Grenier 2012) (as outlined above).

Traditionally the transitions of later-life were seen as widowhood and retirement (Ferraro 2001:314-315). These are the two transitions that receive most research interest (see Ferraro 1984; Chambers 2000, Phillipson 2002; Lee, Min and Chi 2017). Thus, gerontologists still tend to recognise retirement as the dominant transition in older age, paying far less attention to becoming frail or entering the 'fourth age' (Grenier 2012:169-73). And, while spousal loss is especially prevalent amongst the oldest-old, who are also more likely to experience disability, there is little dedicated research focusing on their experience of widowhood (Isherwood, King and Luszcz 2017).

3.4.3 My Approach to the Lifecourse – Social Constructionist

Finally, I clarify here what I mean when I talk about the lifecourse. According to Grenier (2012:21) insights from a critical perspective on ageing and the lifecourse, especially as considered from a constructionist lifecourse perspective, can be used to link understandings of social and cultural structures with subjective experiences and 'can take account of macro and micro elements.'

As I said already, a social constructionist approach to the lifecourse informs my approach and analysis. Thus, because this study seeks to understand experiences of disablement processes (and meanings made of them) by older people, I use an inductive method, namely a constructivist grounded-theory approach (which I will elaborate on in **Chapter 5**) and a social constructionist approach to the lifecourse (see Holstein and Gubrium 2000; Hockey and James 2003). Instead of focusing on predicting relations between 'fixed' variables, this perspective focuses on the interpretive dynamics of the world. As Hockey and James (2003:180) argue, an exclusive focus on macro-level socio-historical accounts does not always result in insights into the embodied experience of ageing. Thus, my approach to the lifecourse centres largely on its constructed nature - examining how people *constitute* the lifecourse through interpretive practice and how experience is made meaningful in relation to the passage of time (Holstein and Gubrium 2000:41)[18]. The focus is on experience as constructed and emergent, but also as 'circumstantially shaped' – or constructed under certain circumstances in which individuals draw from distinctive discourses, interpretive resources, and structures of normative accountability (Holstein and Gubrium 2000:184).

Thus, the focus is on ways that people employ categories and descriptions like 'old age' to make sense of life change (Holstein and Gubrium 2000:3). This means that focusing on change (and terms like 'transition', 'turning point' or 'milestone') involves attending to the *sense* that people have of life having changed (Holstein and Gubrium 2000:34-41). This is consistent with taking a critical gerontological

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[18] Holstein and Gubrium (2000:31) locate the constructionist approach within several sociological traditions, including symbolic interactionism, which suggest that people's depictions of and dealings with their social worlds create those social world as meaningful phenomena.

approach (as characterised by Grenier 2012:12,19), which emphasises the constructed nature of the lifecourse, questions assumptions that are given expression in organisational and institutional practices (in this case, on ageing and on disability), and emphasises subjective perceptions of older people as revealed in narratives.

But key insights of what I call ‘the lifecourse perspective’ can also be said to inform my approach. Specifically, I accept the lifecourse insight that meanings of age are social constructs through which long-term historical trends come to be widely accepted as aspects of human nature, despite their sociopolitical origins (Dannefer and Settersten 2010:12). To help clarify how biographical experiences intersect with wider social contexts, and to facilitate comparison, I sometimes draw on literature in ‘the lifecourse perspective’ and use concepts associated with the lifecourse perspective (such as ‘linked lives’ or perceptions of certain transitions as ‘on-time’). Furthermore, the lack of focus within the lifecourse perspective on lifecourse transitions involving impairment in later-life (Grenier 2012), and the fact that little is known from a lifecourse perspective about the experience of the AwD group (Jeppsson-Grassman *et al.* 2012), form part of the rationale for this study.

I now come to Part 2 of this Chapter, where I focus on empirical studies with the DwA and AwD groups.

PART 2 – Empirical Studies

3.5 Evidence from Empirical Studies

I address empirical literature in this section. In the introduction to this Chapter, I suggested that there are some empirical gaps relative to subjective experiences of disablement in older age. These include the fact that it remains unclear if the social processes are different or similar for the DwA and AwD groups. In this, the second part of this Chapter, I focus on what empirical studies with the DwA and AwD groups suggest about their experiences, and I compare the two.

3.5.1 Empirical Gaps

As I stated in the Introduction to this study, critical/cultural gerontologists highlight how the sociological understanding of ageing *as applied to late older age* is not well advanced (Grenier 2012; Phillipson 2013; Lloyd *et al.* 2014). The meaning and significance that older people attach to disablement processes are overlooked, as biomedical approaches focus greatly on identification of objective conditions of frailty (Grenier 2012:188). Thus, empirical work on subjective experiences of being older and disabled/frail is limited (Kelley-Moore *et al.* 2006; Nicholson *et al.* 2012). Lloyd (2004; 2010; 2012) argues for more attention to how people negotiate the experience of late-life and for their experiences to influence public policies.

At a population level, little is known about the AwD group (Clarke and Latham 2014; Putnam *et al*. 2016) and there is a dearth of literature focusing on them (Grist 2010; Bishop and Hobson 2012;2015; Jeppsson-Grassman *et al* 2012; Putnam *et al.* 2016). Researchers in both gerontology and rehabilitation-counselling suggest that the experiences of the DwA and AwD groups are different (see Garabagiu 2009; Grist 2010). Different aetiologies tend to be highlighted, along with different social and material conditions. Thus, disabled people aged 65+ tend to have different underlying conditions to disabled people aged under 65, with disability in later life often caused by chronic illness rather than congenital/developmental conditions or injury (Verbrugge and Jette 1994). Also, the AwD group can experience early onset of age-related health conditions (or ‘accelerated ageing’), secondary conditions relating to long-standing impairment, and ageing may add further health conditions (Sheets 2010; Iezzoni 2014).

Social and material differences between the two groups are also stressed, involving how the DwA group typically ages after a long period of social inclusion (through, say, employment and/or marriage) and may have accumulated social and financial resources (National Council on Ageing and Older People and National Disability Authority 2006). Whereas for the AwD group, worsening health and impairment often occur against a backdrop of generally poorer health and social disadvantage, including high unemployment, low incomes and educational attainment (Iezzoni 2014).

But questions are now being asked as to whether there may also be some experiences in common between the two groups (Bickenbach *et al.* 2012:1). A large-scale U.S. study (Verbrugge, Latham and Clarke 2017) examined what it characterised as 'persistent disability over a long time period'[19], concluding that it involves significant social and health disadvantages. These researchers suggest that no matter when disability onset occurred, it could have significant negative consequences if experienced for a long time (preventing accomplishment of goals, having to adapt daily life and attitudes, and emotional consequences). They focus on prevalence and correlates of disability, but posit that the social and emotional consequences might be similar for all age groups when disability is experienced for a long time – that is, even if disability is experienced first in later life. They conclude that 'specific goals and problems will vary by age, but overarching life issues are the same'.

Overall, there remains an empirical gap around whether the psychological and social processes for the DwA group are significantly different from those involved for the AwD group (Putnam 2002; Freedman 2014).

3.5.2 DwA: How Disablement is Experienced

There is a small but growing body of empirical work on subjective meanings made by older people of the experience of acquiring physical and sensory impairments – the focus is often on people categorised as frail, but other categorisations used include disability and having health issues requiring support[20]. These studies include the following: Becker 1994; Grenier 2005,2006,2007; Murphy *et al.* 2007, Puts *et al*. 2009; Nicholson *et al.* 2012; Nicholson *et al*. 2013; Lloyd *et al.* 2014; Bontje *et al.* 2015; Thetford *et al.* 2015, Walker, Johns and Halliday 2015; Warmoth *et al.* 2016. Only one of these (Murphy *et al.* 2007), includes a stated focus on people in the AwD group as well as the DwA group, and it did not distinguish the two experiences to any extent in its findings.

As mentioned already, there are also a small number of studies in the sociology of health and illness literature on the concept of biographical disruption in the context of onset of chronic illness in older age (see Pound, Gompertz and Ebrahim 1998;

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[19] They focused mainly on prevalence and compared experiences between groups aged 51+ and 65+, comparing disabled and non-disabled people; they did not attach a specific time period or timing of disability onset to the concept of 'persistent disability over a long time period'.

[20] The focus of this study is the concept of 'disability' not 'frailty', but the two overlap (see Van Campen 2011 and **Chapter 2**). Thus, I include research on subjective understandings of frailty and the fourth age as well as of disability.

Sanders, Donovan and Dieppe 2002; Meijering *et al.* 2016). These explore similar experiences amongst chronically-ill or disabled older people.

Having reviewed these studies, I suggest that they share a number of common issues, including maintenance of a sense of self-identity, control and independence, and how participants employed strategies to address challenges faced. Control over decisions and interactions with services could be important (Walker, Johns and Halliday 2015). Participants focused on activities they could still do and on keeping up social connections (Becker 1994; Murphy *et al*. 2007; Nicholson *et al*. 2013; Warmoth *et al*. 2016). For example, people aged 86-102, categorised as frail, can be involved in creatively working around challenges, characterised as involved in ‘extraordinary work’ to address physical, emotional or social vulnerabilities (Nicholson *et al*. 2013:1179).

Participants could also reject or nuance ideas of having a ‘frail’ identity (Becker 1994; Grenier 2005; Nicholson 2013; Warmoth *et al.* 2016). They described emotional challenges, often associated with loss and fears for the future. The oldest old participants, especially, expressed worries about illness, functional decline and dependency. Thus, over time, loss (of physical capacity, friends, family etc.) is part of their experience (Grenier 2008; Murphy *et al.* 2007; Nicholson *et al*. 2013).

Studies often also highlight social and environmental aspects of the experience along with diversity. For example, in Grenier’s (2005) study, older women understood frailty and disability as related not just to bodies but also to contexts like using public transport or getting around an inaccessible home. One implication, highlighted by Grenier (2005), is that service-provision must move across traditional programme barriers, such as health, ageing and disability, to address overlapping issues (like housing and transport) as well as social location.

3.5.3 AwD: How Ageing is Experienced

There are two contrasting hypotheses about the AwD experience posited in existing literature. On the one hand, a ‘double difference’ (Jeppsson-Grassman 2013:30) or ‘double jeopardy’ is assumed, arising from the overlay of ageing processes on disability (Reyes 2009; Bishop and Hobson 2015). On the other hand, the concept of age as ‘leveller’ suggests that the AwD group may have an advantage from using strategies acquired from living with disability as applied to ageing (Reyes 2009;

Bishop and Hobson 2015). For example, Garland-Thomson (2016) suggests prospectively, from her experience, that experiencing disability early in life will be an advantage because of the resourcefulness developed. Similarly, Iwakuma's (2001) participants felt that difficulties encountered already would confer confidence about coping with ageing.

But there has been little investigation of the AwD experience, especially of physical or sensory disability. Issues of ageing with intellectual disability predominate (Bishop and Hobson 2012; National Disability Authority 2009, Appendix 1). Ageing with physical disability has been neglected (Bishop and Hobson 2012; 2015), and there has been least focus on ageing with sensory impairment (Simcock 2017).

Very few sociological studies compare the experience amongst DwA and AwD groups[21]. An exception is Bulow and Svensson's study (2013:78[22]) focusing, not on physical disability, but on mental health issues, comparing people ageing with long-standing mental health issues with another older group 'needing help of various kinds'. It suggests that the experience of ageing with long-term mental health conditions could be very challenging - getting older involved loss of role for the 'normal 'older group but not for the mentally ill group, but only because loneliness, lack of self-esteem and lack of role had already been a feature of their lives.

The small body of empirical research focusing on the subjective experiences of physical and sensory disability, includes the following studies: Zarb 1993; Zarb and Oliver 1993; Iwakuma 2001; Jeppsson-Grassman 2013; Jeppsson-Grassman *et al.* 2012; Holme 2013; Cooper and Bigby 2014; Bishop and Hobson 2015. One (Larsson and Jeppsson-Grassman 2012) discusses the AwD experience drawing on literature from the sociology of health and illness (and already referred to briefly under the heading of medical sociology, above). There is also a study exploring community participation with this group (Raymond, Grenier and Hanley 2014) and one exploring the concept of successful ageing (Larsson 2013). Participant samples

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[21] From within psychology, Grist (2010), examined concepts of adaption to disability and quality of life scores and found that early onset of disability was associated with greater adaption to disability although it did not affect quality of life scores.

[22] Swedish comparison study of people ageing with a lifelong mental illness (7 people aged 60-76) with an already completed study with 10 older people 'well past retirement age' and 'needing care of various kinds' but with no history of mental illness (2013:78).

are quite small in some of these studies[23] and they come from a range of countries, meaning there is a range of differing backgrounds, including policy frameworks. The experience of sensory impairment is not well-represented amongst them, but Simcock's (2017) systematic review of the literature suggests that some similar issues may affect deafblind people.

Participants in these studies were heterogeneous and there is a variety in ways in which this group experiences the transitions of later life – it is clear that there is no one AwD experience. Some experienced lives that had been dominated by a 'gradually failing and unpredictable body' (Jeppsson-Grassman 2013:32). They could experience decreased mobility/agility over time and liken the effects of ageing to onset of a 'second disability' (Zarb and Oliver 1993). They could perceive that they were ageing faster than others (Zarb 1993) and that continuing to survive and maintain control was made harder by ageing (sometimes linked with a certain pride in having endured difficulties throughout life) (Zarb and Oliver 1993; Cooper and Bigby 2014).

On the other hand, some lived active, self-fulfilling 'third age' lifestyles and were similar to any 'third-agers', despite needing help with mobility or dressing (Jeppsson-Grassman *et al*. 2012), in that case facilitated by public policy responses in Sweden. Life could become more normalised in that it began to look more like the lives of other older people (Jeppsson-Grassman *et al.* 2012; Bishop and Hobson 2015). And some felt confident that they would cope with additional problems (Zarb and Oliver 1993; Iwakuma 2001; Holme 2013; Bishop and Hobson 2015). Thus, it is possible to see support for both the 'double jeopardy' theory of ageing with disability *and* the contrasting concept of age as 'leveller.'

One distinction from the DwA group was that several studies suggest that a sense of identity as disabled people – and maintaining that identity now - could be important to participants, sometimes linked to a sense of collective experience (Jeppsson-Grassman *et al*. 2012:102; Holme 2013; Cooper and Bigby 2014). But again, the participants were heterogeneous, as some stressed that they had lived an 'ordinary' life, and included themselves amongst those growing older (Raymond, Grenier and Hanley 2014:57-58).

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[23] For example, Holme's study included 8 participants (Holme 2013). The Bishop and Hobson (2015) study involved 7 people. Another (Jeppsson-Grassman 2013) had a small sample size (14 participants) but followed them over decades.

Like participants in the DwA studies, participants made efforts to maintain independence and control and they experienced losses and fears, especially of dependence. Fears – especially about a lack of support - could be worse for women (Zarb 1993; Zarb and Oliver 1993).

Studies often highlight the importance of social and material context, including public policies. Maintenance of relationships could be hampered by mobility and transport issues. Thus, personal financial resources and community care were important to maintaining independence and control (Zarb and Oliver 1993; Cooper and Bigby 2014). Early disability onset could significantly affect the experience of older age, particularly if it impacted on access to work and hence access to retirement savings/plans (see Bishop and Hobson 2015).

Finally, several studies highlighted challenges of using aged-care services, such as difficulties in accessing them (and sometimes reluctance to access them) or difficulties accessing appropriate professional care (Zarb 1993; Zarb and Oliver 1993; Cooper and Bigby 2014). Some felt that self-management and social roles were threatened by the nature of aged-care services and they 'did not want to be submerged within the ranks of the ageing' (Cooper and Bigby 2014:431). Participants in one study (Bishop and Hobson 2015) could lose services but also gain in income when they reached age 65 – and that varied depending on the position of each person.

3.5.4 Experience of the two Groups Compared

To summarise, key issues on which **commonalities** can be seen between both groups (DwA and AwD) related to (1) the dynamic nature of the experience at a bodily level, (2) strategies to maintain a sense of self-identity, control, independence and connection, (3) the relevance of social and contextual factors, as within both groups are people experiencing difficulty due to lack of financial and social resources, and (4) the experience of loss and fears for the future.

Key issues on which **differences** are in evidence relate to (1) a 'disability' identity – participants amongst the AwD group sometimes attached importance to their sense of identity as disabled people, (2) 'normalisation' - for some amongst the AwD group as they aged life could become more like the lives of other older people, and (3) some of the AwD group had difficulty obtaining appropriate professional services, and could perceive that mainstream aged services threatened their self-management and social roles. It is also clear that the consequences of long-standing disability for some of those within the AwD group included being poorer in older age.

Overall, this review highlights the degree of effort that participants from both groups invest in maintaining a sense of self, in continuing to exercise choice, in working around challenges and keeping connections – often in the face of a dynamic worsening of impairment/health over time. These efforts tend to be unrecognised in the predominant stereotypical image of the frail older person. I suggest also that public policy approaches that now focus hugely on those in the third age may not sufficiently take account of these experiences, including the degree of loss and the consequent emotional challenges that can be experienced by both groups.

Furthermore, a simplistic binary understanding of disability experienced first in late life (DwA) versus ageing with disability (AwD) may not sufficiently take account of diversity within each group, or common challenges they face. For both groups, more sociological research from the perspective of older people is needed and there are almost no studies that address the experience of disability across the two groups (DwA and AwD).

3.6 Discussion

In this Chapter, I reviewed key theoretical approaches within gerontology, disability studies, medical sociology, and lifecourse studies. I also reviewed empirical studies of subjective experiences of disablement with the DwA group and of ageing with the AwD group. My review supports the contention I made at the outset that there are only separate theories on ageing and on disability and confirms the need for more empirical work on the experience of being disabled/frail to inform both social gerontological perspectives and public policies.

While there is some limited focus within critical disability studies and medical sociology on ageing, these fields remain largely separate from that of gerontology (as well, for the most part, from each other). In general terms, gerontological approaches insufficiently acknowledge social and economic consequences of impairment or disability in older age (Kelley-Moore 2010; Phillipson 2013), and disability theorising focuses on issues for children and young adults leaving disabled older people out of the picture (Kennedy and Minkler 1998; Priestley 2006; Thomas and Milligan 2018). The fact that few gerontology scholars identify as older distinguishes social gerontology from disability studies, which has always been more aligned with disability activism. I suggest that gerontology is the poorer for this. However, while many disability theorists identify as disabled, that does not include disabled *older* people, something that deprives efforts to bridge the two fields of important contributions.

I identified similarities in the course that theorising has taken within the field of gerontology and disability studies. Critical/cultural studies (encompassing a range of perspectives) are now significant in both. Both fields include a focus on cultural representations, bodies and on identity. There are similarities in accounting for the marginalisation of both groups in cultural representation, associated with perceived dependency and denial of full personhood. Both fields now include a focus on the body, and yet by focusing on discourse rather than lived experience, cultural or critical studies can sometimes seem to deny the reality of impairment and remain at a remove from lived experience (see Shakespeare 2014a), and at the greatest remove from bodies of the oldest old. Furthermore, approaches to ageing based on ‘successful’ ageing (and similar) concepts may reinforce stigmatising views of disability in later life by framing disability as a matter of failed personal responsibility (McGrath *et al*. 2016).

Scholars writing on ageing from a moral economy or cultural perspective suggest that the issue of meaning in life may become a particularly important issue for later life due to the amount of change involved. Yet the issue is not often apprehended directly and there are few explorations of meaning in later life with older people (Edmondson 2015). And there is little/no exploration in the literature specifically of meaning in life amongst older people who experience disability (or are in the ‘fourth-age’), arguably the group who are experiencing the greatest challenge to meaning, due to the degree of change they experience.

Some lifecourse studies within the two fields of ageing and disability include a focus on the experience of older disabled people or the fourth age (see Priestley 2003a; Grenier 2012). But knowledge of disability and ageing is still under-developed and the experience of disability in older age, and the transitions it involves, are not well understood either within what I call the lifecourse perspective (associated with

Elder) or within what I refer to as lifecourse studies in gerontology (see Grenier 2012:169-182; Jeppsson-Grassman *et al* 2012). Least of all is known about the experience of the AwD group.

My review of empirical studies with those in the DwA and AwD groups suggests that, while there were some differences, a simplistic binary understanding between disability experienced first in late life (DwA) versus ageing with disability (AwD) may be open to challenge. Empirical studies showed that both groups invest effort in maintaining a sense of self, in continuing to exercise choice, in working around challenges and keeping connections, as well as the high degree of challenge at an emotional level associated with experiences of loss. For both groups, more sociological research from the perspective of older people is needed. One implication is that this study has potential to make a contribution, because there are almost no studies that address the experience of disability across the two groups (DwA and AwD) as this study does.

Critical gerontologists now highlight the need to move away from an exclusive focus on physical (or individual) health issues or impairments to an external and social engagement with the experience of late older age (see Grenier 2005; Kelley-Moore 2010; Phillipson 2013). Some suggest that gerontologists could learn about the social construction of disability from disability scholars (Kelley-Moore 2010; McGrath *et al.* 2017) and some use concepts developed within disability studies to focus on aspects of experience of late-life disability. But overall, while scholars often use similar paradigms to explore ageing and (separately) disability, the two fields progress on parallel tracks. Thus, while critical approaches have capacity to explore in greater detail issues of impairment and disability in older age, most critical approaches focus *either* on disability or ageing (Grenier, Griffin and McGrath 2016).

Within disability studies, Davis (2013a:272) identifies the need to explore how older people define disability. Correspondingly, within gerontology, Grenier (2012:188;189) and Lloyd and colleagues (2014) call for more investigation of how the ‘fourth age’ is defined, of how older people interpret/negotiate it and of the meaning and significance they attribute to the transition to it.

I locate this study within a critical gerontology approach – particularly within its moral economy or cultural strand – and my approach is informed by a social constructionist approach to the lifecourse. This is because the focus on subjective experiences within a wider context in both these approaches match this study's exploration of experiences and meanings made of disablement by older people and of how their experiences interact with socio-cultural discourses and policy-environments.

3.7 Conclusions and Implications

I conclude that scholars often use similar paradigms to explore ageing and (separately) disability, with critical/cultural studies now significant in both. However, the two fields largely progress on parallel tracks. My review confirms that there a need for more empirical work on the experience of being disabled and older, and that within existing literature the AwD experience is particularly under-explored.

A key insight of social models of disability and critical disability studies (also reflected in medical sociology approaches) – that disability is not just a personal, individual issue and that it is in part at least socially created – has yet to be applied to any extent to the experience of disability in older age. This study in exploring different experiences of disablement and disability in older age seeks to make a contribution to a developing - but under-developed field – that of bridging the two areas of disability studies and social gerontology.

Concluding Remarks

This Chapter forms a reference point for the rest of the study by reviewing the relevant theoretical literature and relevant empirical studies. It also clarifies what I mean by a constructionist lifecourse perspective, which informs this study. In the next Chapter, I further contextualise the study by reviewing public policy on ageing and disability, mainly in Ireland but also internationally, and I examine statistics on the prevalence and nature of disability and ageing. I discuss the implications of the separate policy-frameworks (that is, between disability and ageing) for older disabled people and I suggest that the extent to which disability prevalence and severity rises with age is under-recognised in general perceptions of what 'disability' is.

CHAPTER 4: PUBLIC POLICY AND STATISTICS ON AGEING AND ON DISABILITY

4.1 Introduction

In this Chapter I examine the separate public policy frameworks for ageing and disability. In doing so, I address how public policy underscores difference between people with different timings of disability onset because it operates as if people are *either* disabled or older, *not* both (Bigby 2008), as outlined in the Introduction to this study. I examine how disability and ageing are separately constructed within the two frameworks. Social care is the main focus of this Chapter because it is an overlapping area of public policy for both policy frameworks. I review policies addressing physical and sensory disability, because that disability-type is the focus of this thesis (see **Chapter 5**).

There are three parts to this Chapter. I first review explicit policies in Ireland on ageing and on disability and how they have changed over time. I discuss the interface (or lack of it) between the two sets of policies and the implications of this. In the second part of the Chapter, I consider some comparable issues in policies and practices in other countries and discuss approaches aimed at bridging the fields of disability and ageing. In the third part, I present statistical information on ageing and disability, illustrating how disability prevalence and severity rise with age, making it less justifiable that older people are left out of disability debates, and highlighting the anomaly of totally separate policy frameworks on ageing and disability.

Within Irish disability policies, I found that there is little acknowledgement of disability in older age (whether for those experiencing disability with ageing (DwA) or ageing with disability (AwD)), and within older people's policies, there is no emphasis on the AwD group. Confirming the proposition set out in the Introduction to this study, I found that the two frameworks operate out of different models of disability, with disability policy influenced by social model and human rights approaches, and older people's policies operating out of the narrower medical model. I found instances of each sector reproducing, respectively, ablest or ageist assumptions and no indication of an active interface or learning from the other. An implication is that if the two sectors are to learn from each other, then they first need to develop shared ways of understanding what disability is.

It is significant – both for identities of older people and in respect of how services operate in practice - that current Irish policies on ageing, mirroring developments internationally, focus on active or positive ageing, but lack a focus on what positive ageing means for disabled older people (whether from the DwA or AwD groups).

This Chapter concludes that it is not clear in explicit policies which service is responsible for the AwD group from age 65 nor, therefore, what happens in practice at that administrative boundary. I explore this issue in this study through interviews with policy-makers and others (see **Chapter 6).**

4.2 Background - Irish Policy on Ageing and on Disability

In Ireland, services are organised around separate categories of disability and ageing (using age 65 as the boundary). Separately funded ageing and disability sections operate within the Department of Health and the Health Service Executive (where both are in the Social Care Directorate) (Department of Health 2013a). Separate funding streams militate against boundary-crossing and create difficulties for some groups, such as those with early onset dementia (Conroy and Mangan 2006). The Disability Federation of Ireland (2009; 2014) highlights anomalies, including the fact that those experiencing disability after age 65 do not have access to the same range of services as those experiencing disability prior to age 65.

In the next two sections, I review key approaches within ageing and disability policies. In **Table 4.1**, below, I include a summary of key characteristics of the two in terms of policy development and service delivery.

4.3 Ageing: Social Care Services – Overview and Conceptualisation

In this section, I discuss key services provided by way of social care for older people, the evolution of policy frameworks, and how they conceptualise ageing.

4.3.1 In Practice: Community Services for older people

Home Help support (involving light housework) is traditionally the main service supporting older people to live at home (Haslett *et al*. 1998). Home care packages (introduced, 2006) can provide a wider range of supports. Private sector provision is increasingly significant (Pierce 2008). Other supports to live at home include Day Care and local community/district hospitals providing a range of services, often nurse-led and supported by GPs.

Residential care is financed through the statutory Nursing Home Support Scheme (or Fair Deal), involving state and user co-payment and a posthumous charge on the care recipient's home. By contrast, homecare is not yet underpinned by legislation.

Despite an ageing population (see below), levels of Home Help fell between 2008 and 2015 and funding for home care packages was largely static (Healy *et al.* 2017). The Health Service Executive (2015) acknowledges that supports provided often fail to match requirements.

4.3.2 Strategies: Key Developments and Conceptualisation

Currently the most significant policy framework on ageing is *the National Positive Ageing Strategy* (2013), informed by the World Health Organization's Active Ageing Policy. Framed as cross-departmental, it is broader than health and social care, which was a new departure in terms of Irish ageing policies. A group that included national organisations in the age-sector inputted into its formulation as did one disability organisation. No comprehensive implementation plan exists but some consultation on this occurred in 2017 (see Department of Health 2017a).

The *National Positive Ageing Strategy* sets goals/objectives (participation, health, living at home, research on ageing) to promote positive ageing (Department of Health 2013b:19). An objective under the health goal refers to 'high quality care services and supports' (Department of Health 2013b:20). The Strategy does not detail services for ill or disabled people, and the chief context in which residential care is referenced relates to its funding (an action under goal 2.2). The issue of care (or its values, aims, intended outcomes) is not emphasised; instead the strategy promotes independence and a self-managed approach to health for older people who have not developed illness or impairment. It does not articulate how ageing well, when experiencing impairment, should involve maintaining autonomy, well-being, and one's sense of identity (Wahl, Iwarsson and Oswald 2012:310). Thus, it lacks a focus on what positive ageing means to older people experiencing disability.

The words 'independent' and 'independently' occur frequently and 'dependent' tends only to be used in reference to how older people have been unhelpfully characterised in the past (Department of Health 2013b:5,8,12). The main context for referring to 'disability' relates to its prevention. However, there is one reference to 'dependent' people in the form of 'older more dependent' people who are to benefit from volunteer support of other older people to protect them from isolation

(Department of Health 2013b:26). Thus, a category of older people is still characterised as ‘dependent’, used as a proxy for impairment, disability or chronic illness. This reflects a biomedical approach in which disabled older people can be categorised by degree of dependence (see Woodhouse *et al*.1988 and discussion in **Chapter 2**).

There is no engagement with what ‘dependency’ means or acknowledgement of its contested nature – these being debates that occur mainly within disability scholarship and activism (see Fine and Glendinning 2005:605). Thus, there is no explicit awareness that while impairment can generate forms of dependency, it can also be a product of (or compounded by) social arrangements (see Morris 1999; Good and FitzGerald 2005; Fine and Glendinning 2005; Murphy *et al.* 2007; Shakespeare 2000a,b;2006:147).

The *National Positive Ageing Strategy* represents a major shift from earlier strategies in how ageing is constructed. The *Care of the Aged* Report (Government of Ireland Interdepartmental Committee 1968) was introduced at a time when institutional care was almost all that was available. It framed ‘the aged’ as a serious problem associated with physical, sensory and cognitive decline, ill-health, isolation and loneliness, thought to be *inevitably* associated with ageing (Interdepartmental Committee 1968; Pierce 2008). Older people were not consulted in its framing (Pierce 2008). Subsequent strategies were similar in their framing, like that from 1988, where the phrase ‘dependent elderly’ describes older people needing services and supports (Working Party on Services for the Elderly 1988:26,178).

While the 1968 strategy endorsed care in the community and made wide-ranging recommendations (including development of geriatric hospitals, respite and convalescent care, assessment and rehabilitation), subsequent reviews identified continuing gaps and a bias towards long-term institutional care (Working Party on Services for the Elderly 1988:184; Ruddle, Donoghue and Mulvihill 1997:5; Department of Health and Children 2001). And, while levels of investment in services for older people increased from the late 1990s, key recommendations of the 1968 report have still not been implemented (O’Neill 2015).

Other notable developments over time (though not articulated in explicit strategies) include a shift during the 1990s and 2000s towards encouraging private sector involvement through public subsidisation of private nursing homes, including tax incentives for building them.

4.4 Disability - Social Care Services – Overview and Conceptualisation

I turn to disability policies in this section – meaning policies for disabled people generally, which traditionally do not take account of people aged over 65. I set out key services provided, consider the evolution of policy frameworks and discuss how they conceptualise disability.

4.4.1 In Practice: Community Services for disabled people

Community-based services can include assisted living/personal assistant services, including Home Support and Personal Assistants. Personal Assistants can offer a broader range of services than help with tasks of daily living, facilitating work or other activities. Particularly valued, this allows self-direction and more freedom of participation (Quin 2003). However, advocates describe the Personal Assistant scheme as ‘an orphan in Ireland’s social policy framework’, not integral and (where it exists) narrowed in focus due to cut-backs (Disability Federation of Ireland 2014:13). Other community-based services include day centres offering recreational/health facilities (Quin 2003). Between 2008 and 2015, there was a 9.4% reduction (excluding inflation) in spending on disability services while demands increased (Social Justice Ireland 2017).

4.4.2 Strategies: Key Developments and Conceptualisation

Traditionally, disability services segregated people into institutions and were conceived of as part of health policy. The traditional framing changed when a Green Paper from 1984 envisaged a broader approach. The *Report of the Commission on the Status of People with Disabilities, A Strategy for Equality* (1996) was a watershed, making wide-ranging recommendations across all areas of government. It articulated three informing principles:

- disability as a social issue not a medical one;
- a civil rights perspective; and
- equality as a key feature of the human rights approach.

This positions disability within social models and it promotes rights (Linehan *et al.* 2014).

Legislation (the Disability Act 2005) and a series of measures introduced in 2005 amounted to a National Disability Strategy[24] whose main objective was supporting disabled people to be active and contributing members of society and involving mainstreaming of disability issues across government departments. However, lacking a legal basis for its commitments, key aims have not been realised nor have key provisions been commenced (Jenkins 2013). Potentially significant, from the perspective of this review, the Disability Act (2005) includes a definition of 'disability' wide enough to encompass older disabled people, and, thus, has potential for closer integration between ageing and disability services (Conroy and Mangan 2006; Murphy *et al.* 2007).

Development of an implementation plan for the Disability Strategy 2013-2015 involved a stakeholder group without representation from any national organisation for older people[25] (National Disability Strategy Implementation Group 2013), notwithstanding the high proportion of people aged 65+ amongst disabled people (see **Table 4.2,** below). Although the implementation plan recognises that disability is an issue for *all ages*, disability policies do not for the most part focus on the needs of older disabled people, whether from the DwA or AwD group. The former (DwA) are sometimes excluded explicitly. For example, a high-level review of disability policy excluded those in receipt of older people's services from its review – older people in receipt of social care were not considered 'disabled' (Expert Reference Group on Disability Policy 2010). For their part, the AwD group is sometimes assumed to be encompassed in policies/services on ageing (which I return to below).

Other policy directions of recent years include de-congregation from residential settings. More user control is now a significant issue (Expert Reference Group on Disability Policy 2010; Department of Health 2012b; see also, Department of Health 2012a). In 2016, a taskforce was announced relative to personalised budgets[26] for

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[24] Key measures envisaged needs assessment (Disability Act 2005), personal advocates (Citizens Information Act 2007) and provisions relative to education (Education for Persons with Special Needs Act 2004).

[25] The group comprised key Government Departments, the County and City Managers Association, the National Disability Authority, and a newly configured Disability Stakeholders Group made up of seven disability organisations as well as disabled individuals.

[26] Countries use a range of personalised or individualised models (Anand *et al*. 2012). In the U.K. a personal budget can be managed by the local authority or by a third party that commissions services for users, or it can be given to users or their carers as a direct payment (National Audit Office 2016:5). Disabled activists are especially associated with campaigns for direct payments (Glasby 2011).

social care (Department of Health 2016a). Published information suggests that the taskforce consists of a Strategy Group whose membership includes representatives of ‘people with intellectual disabilities and physical & sensory disabilities’ (Department of Health 2016c:2) but not groups representing older people. A public consultation process started in October 2017.

Overall, the disability sector has received a lot of policy attention[27]. However, a national review suggested that services do not meet stated policy objectives with little opportunity in practice for self-determination (Expert Reference Group on Disability Policy 2010).

That disability and aged-care frameworks show differences in aims, values and conceptualisation can be illustrated by reference to the 2001 National Health Strategy, stated as aiming to achieve ‘potential’ and ‘independence’ for disabled people:

> …to enable each individual with a disability to achieve his or her full potential and maximum independence, including living within the community as independently as possible (Department of Health and Children 2001:141).

There was no comparable principle for older people whose ‘needs’ were tied to demographic ageing and increased demands on services (Department of Health and Children 2001:54;70;149).

These kinds of distinctions continue in recent Health Service Executive service plans. For example, the plan for 2017 articulates aims for disabled people that include fulfilment of potential, ordinary lives in ordinary places lived ‘as independently as possible’ (Health Service Executive 2016:30). Their voices are to influence services. However, aims for older people focus on efforts to ‘maintain’ them in their homes and communities, while also referencing the need for availability of residential care. Thus, for older people there is no reference to independence, participation in communities or for input into service planning or improvement.

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[27] These include the National Housing Strategy for People with a Disability, 2011-2016; Report of Disability Policy Review (2011), Value for Money and Policy Review of Disability Services (2012). There are also policies on specific disability types and contributions from the ESRI and NESC.

4.5 In Practice: Interface between Policies on Ageing and on Disability

The separate policy approaches reviewed in previous sections suggest that a strict division is made between disabled people's services and older people's services. This raises the issue of how that separation of the two addresses the intersection of disability and ageing across the lifecourse of individuals, for members of the AwD group. Another issue is why approaches within disability services are not applied to disabled older people (DwA group).

Policies for the AwD group are not well developed (Anand *et al.* 2012), something not confined to Irish policy, as significant numbers of people ageing with disability is a relatively new phenomenon (see Bigby 2002). This is so notwithstanding distinct issues for this group – such as risks of secondary conditions and premature ageing (La Plante 2014), and life histories sometimes involving lack of employment history resulting in few retirement resources (Bigby 2002).

My review suggests that it is not entirely clear from explicit Irish policy which service is responsible for the AwD group. The approach, in-so-far as that is made explicit, can be illustrated by reference to the report of a high-level steering group of disability policy (which, as already mentioned, excluded the DwA group from its remit) (Expert Reference Group on Disability Policy 2010). For the AwD group, the report suggests at one point that older people's services are the appropriate ones (p. 53), and, consistent with this, it excluded from review 2,643 records on the National Physical and Sensory Disability Database relating to people aged over 66 (that is, people availing of specialised disability services who experienced disability at least before age 65), saying:

> responsibility for provision of services to this group lies within older people's services rather than disability services' (p.24).

However, it qualifies this approach elsewhere by adding:

> Older people with disabilities should have access to services for older people <u>if</u> their needs are best met within that service setting (p.53). [my emphasis]

In a similar vein – an assumption that the AwD group is absorbed into older people's services at age 65 - the policy on Day Care, *New Directions* (2012), strictly distinguishes between clients aged under and over 65, and focuses mainly on employment and community participation for those under 65. Clients over 65 are to come within older people’s services, and it recommends that they have:

> access to a continuum of support that respects their rights, dignity and choice and is provided within the relevant older person’s policy and legislation (Working Group Report (HSE) 2012: recommendation 9,122).

Thus, it assumes that employment and community participation should stop for the AwD group at age 65 and it shifts the focus at age 65 to ‘support’. This reflects an ageist assumption that people over 65 do not require community participation and are dependent, and that everyone of working age is independent, and applies it – perhaps somewhat paradoxically - to a group already in receipt of disability services.

Furthermore, policy does not address the implications of absorbing the AwD group into older people’s services at age 65. For example, there is no commitment to upskilling and resourcing those working within older people’s services to deal with their needs. The needs of the AwD group involve complexity in research and practice (La Plante 2014), and empirical studies suggest that they can perceive that health professionals or older people’s services do not understand their impairments (see Cooper and Bigby 2014; Simcock 2017).

Finally, two separate - and potentially overlapping - initiatives are underway in Autumn 2017, from the disability and older people’s sections of the Department of Health, respectively. The first proposes a personalised approach in social care designed to facilitate increased levels of choice and control (Department of Health 2016a). The second relates to homecare concerning proposals for a new statutory scheme (Department of Health 2017b). Thus, even the most recent developments in this field reflect a bifurcated approach to ‘disability’ and ‘ageing’ categories, despite the intersection of the two. Instead, advocates point to the need for an approach that addresses homecare across the lifecourse (Active Ageing Partnership *et al.* 2017). I finish this section on Irish policies with **Table 4.1,** which summarises features of ageing and disability policy and service models.

Because the bifurcation of public policies on disability and on ageing also occur in other countries, and because there have also been some initiatives that bridge the two, I turn next to put the above discussion in an international context.

Table 4. 1 Comparison Disability and Ageing Policy and Services

Public Policy	
DISABILITY	**AGEING**
Characteristics of Policy Development	
A social or bio-psychosocial understanding of disability informs policy-making (i.e. disability contributed to by culture/attitudes/environments). People ageing with disability sometimes stated to come under policies for older people in explicit policies.	‘Disability’ *per se* not developed as a concept in discussions of illness/care in older age, and some categories of people still characterised as ‘dependent.’ Current *National Positive Ageing Strategy* has no explicit emphasis on disability except its prevention. No focus on issues for people ageing with long-standing disability (AwD).
Values of independence and maximising potential and participation.	Emphasis on maintenance and living independently at home for as long as possible.
National strategy underpinned by legislation. Mainstreaming underpinned by legislation and sectoral plans required of government departments. Long-standing involvement of disability stakeholders in policy development.	National strategy is cross-departmental. No underpinning legislation or statutory requirement for sectoral plans. Developments (such as increased involvement of private nursing homes) took place outside of articulated policy priorities.
Characteristics of Service Delivery	
Community care - Home Care Attendants and (some) Personal Assistants – the latter designed to offer choice and facilitate independence. Move away from residential/congregated settings. Mainly an administrative approach though policy envisages a shift to individualised budgeting. Most services provided through the voluntary, non-profit sector.	Community care – Home Helps and Home Care Packages with growth of private provision. Residential/Nursing home care (largely provided by private sector and partly funded through own assets) is most significant. Statutory scheme for access to institutional care, not for homecare (though policy development is taking place). Administrative approach in which health service determines type and timing of support. Services provided directly by the Health Service Executive, by voluntary organisations and increasingly by the private sector.
Common issues in Service Delivery	
Delays in implementation of stated policy and mismatch between policy values and services. Discretionary - no entitlement. Demand exceeds supply. Contraction of resources following 2008.	

4.6 International Perspectives

In this section I briefly review international framings of policies on active ageing and their consequences. I look at the issue of the traditional separation of public policy on ageing and disability in several countries and refer to cases of integration/alignment between the two sectors.

4.6.1 Older People's Policies Generally – Focus on Active Ageing

As discussed above, the Irish *Positive Ageing Strategy* reflects international approaches to framing of policy for older populations influenced by active ageing approaches. But critical gerontologists, in particular, critique these approaches.

West and Glynos (2014: 6,7,8) suggest that something is 'being missed' in policy frameworks, 'a framing which itself feeds off, and reinforces, the cultural demands of those in the third age'. Lloyd (2012) suggests that active ageing policies have been shaped by larger economic imperatives to reduce demand on healthcare, reflecting a preoccupation with economics/organisation of care and less concern with the *practice* of care, preferably done within the family. Instead of focusing on what kind of care is needed, and how it is experienced, the focus is almost exclusively on demand, supply and funding of services (Lloyd 2012).

Thus, Irish policies are consistent with international approaches reflecting polarisation between third and fourth ages (see Grenier 2012:83) and this emphasis on active participation has the potential to marginalise disabled older people (see Raymond and Grenier 2013).

4.6.2 Problems Arising from Separation and Alignment

My review suggests that, as in Ireland, policies on disability and on ageing are traditionally organised separately in other countries. Complexity and confusion can characterise these separate approaches (Priestley and Rabiee 2001; Putnam 2007) resulting in variations in organisational missions, distinctive professional training, and competition for programme funding (Putnam and Stoever 2007; Putnam 2011; 2014). Bigby (2008) suggests that the strict division between the two may result in the AwD group not being able to access specialised aged-services, and there is a risk that their experiences of premature ageing may be overlooked (Bigby 2008; La Plante 2014).

An international trend, originating in disability activism, involves personalisation or individualisation schemes intended to offer greater choice and control in social care[28] (Pike, O'Nolan and Farraghar 2016:6). There are different models, and transitioning to them is complex financially, politically and practically (Anand *et al*. 2012). Some countries copper-fasten traditional distinctions between disability and older people's programmes by limiting access to personal budgets by age (Anand *et al.* 2012). For example, in France, care for disabled and older people operates separately; in home care, benefits for disabled people are more generous (Le Bihan 2016). Anticipating population ageing, a change in 2016 copper-fastened the boundary because it would require 'significant resources' to extend disability provision to older people (Le Bihan 2016:2).

And in Sweden a valued system of personal assistance for disabled people (from 1994) initially excluded those aged 65+: legislation subsequently included them, but only *if* impairment had manifested *before* that age (Jönson and Larsson 2009). Jönson and Larsson (2009) highlight this as a form of institutional ageism, giving rise to situations where people of the same age with similar needs may receive different standards of assistance.

Other countries take different approaches. In the U.K., disability services traditionally targeted those aged up to 64, transferring people to older people's services afterwards (Simcock 2017) and there was relatively little exchange between policy-making in disability and ageing (Priestley 2002). Older people received a narrow range of services with few receiving rehabilitation and social support (Bowling, Farquhar and Grundy 2008). However, the personalisation agenda, associated with disabled activism (see Morris 1993; 2006; Oliver 1990), resulted in something of an alignment of the two sectors in social care, as anyone eligible for social care is now to be offered a personal budget (preferably a direct payment)[29] (Woolham *et al*. 2017). Disabled activists are especially associated with campaigns for direct payments (Glasby 2011), but older people are the largest group of social care users (Woolham *et al.* 2017).

Studies suggest that the personalisation agenda is not serving older people well (see Glendinning *et al.* 2008; Lloyd 2010; Glasby 2011; Rabiee, Baxter and Glendinning 2016; Woolham *et al*. 2017). For example, one study suggests that

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[28] See the reference to Anand *et al*. 2012 and National Audit Office 2016 in a previous footnote.

[29] See above. In the U.K. a personal budget can be managed by the local authority or by a third party that commissions services for users, or it can be given to users/ their carers as a direct payment (National Audit Office 2016:5).

older service-users did not perceive much control to tailor services to their needs/preferences through using managed personal budgets; instead, low levels of funding and other spending restrictions constrained their choices (Rabiee and Glendinning 2014). Recent contributions query whether in fact the benefits of personalisation are available to most older people (Rabiee, Baxter and Glendinning 2016; Slasberg and Beresford 2016) and suggest that a two-tier system is operating, in which older service-users have experienced little change (Slasberg and Beresford 2016). However, research also identifies *potential* to promote personalisation amongst older people (Rabiee, Baxter and Glendinning 2016).

But these changes have been implemented simultaneously with reductions in funding (Slasberg and Beresford 2016). Older people are not the only groups to experience problems with personalisation or with the way it is implemented (see Duffy 2012; Zarb 2013; Graham 2015; Glasby and Littlechild 2016). For example, lack of emphasis on the interpersonal or relationship aspects of supports purchased using direct payments is considered problematic for (younger) intellectually disabled people (Graham 2015) *and* older people (Woolham *et al.* 2017). However, researchers tend to approach these issues either from the perspective of disability *or* ageing.

I conclude that while artificial distinctions based on chronological age risk overlooking needs and desires for personal autonomy that bridge age groups (Kennedy and Minkler 1999), applying approaches associated with disability activism to the social care of older people without sufficient scrutiny of all the issues can also produce disappointing results. It is also possible that both groups (disabled people generally and older people) experience similar problems with the operation of personalisation that bifurcated approaches to research/evaluation do not fully explicate.

4.6.3 Challenges and Successes of Greater Integration

There are international examples of approaches to integration or bridging between ageing and disability services that are instructive about the challenges and successes involved. Space does not allow a comprehensive review of these approaches, but I refer to some of the issues that have emerged in the U.S.

There long-term homecare was traditionally considered unsuitable for severely disabled older people, who were assumed to need facilities with 24-hour staffing.

But greater integration in supports for disabled adults and older people followed a Supreme Court ruling in 1999 (Putnam 2011). What was ‘unimaginable’ a few decades ago has happened - numbers of older people served through home/community-based services (through Medicaid) are greater in many states than numbers served through nursing homes (Eiken *et al*. 2016: Applebaum and Mahoney 2016:138).

Putnam (2011) identifies a number of challenges of amalgamating or aligning disability and ageing programmes. These include different orientations of staff and limited experience of working with both older and younger disabled people. For example, professional investment in age-segmented policies meant that staff could emphasise life stages, sometimes reproducing stereotypical notions about what services older people might need (bingo and card-games in one case). Thus, perceptions of professionals involved are thought to play a key role in successful alignment of disability and older people’s programmes, but exploration of this is limited (Putnam 2011). Successful working with unfamiliar client groups required training and support (Putnam, 2011;2014; Keefe 2014). This echoes a U.K. study which found that both inadequate training for staff/practitioners and inadequate resources were barriers to greater choice/control for older people within the personalised approach (Rabiee, Baxter and Glendinning 2016).

I conclude that there are conceptual, financial, political and practical considerations that need interrogation as part of attempts to amalgamate disability and older people’s services, and that these do not always get sufficient attention in attempts to align or amalgamate disability and older people’s services. Sustaining bridges between the two fields is challenging (Putnam 2007). However, there are some examples emerging that suggest what factors need to be addressed as part of these changes. Overall, this review underlines Putnam’s (2014) argument that building capacity to conduct bridging research should be a high priority for practitioners, policy makers and scholars working in ageing and disability fields.

I turn next to the third section of this Chapter where I briefly outline the prevalence and some characteristics of disability in older age.

4.7 Disability and Ageing: Statistics

When it comes to national and supra-national statistics, estimates of disability prevalence represent one area where older people are usually counted within the category ‘disabled’. Thus, statistical approaches defy the tendency for separate thinking on ageing and disability outlined in the Introduction to this study and seen in the separate public policy frameworks discussed above. I look first, and briefly, at international statistics and then at Irish disability statistics. Overall, I show that high rates of, and severity of, disability in older age makes it more puzzling, and less justifiable, that older disabled people are left out of debates on disability (see Shakespeare 2014a; Priestley 2006; Thomas and Milligan 2018). It also makes less defensible approaches within social gerontology (like ‘successful’ ageing) that overlook embodiment, involve unproblematic support of positive cultural images, and fail to grasp what Holstein and Minkler (2007:15) characterise as the ‘twin poles of ageing’ – its ‘celebrations and its pains’.

4.7.1 World: Ageing and Disability Prevalence

Global ageing is a major influence on disability trends due to the higher disability risk at older ages, and populations are ageing at an unprecedented rate (World Health Organization and the World Bank 2011). Debates exist about whether disability has been postponed (Bowling and Dieppe 2005), as several studies suggest that rates of disability have declined in recent decades, but the evidence is sometimes conflicting (Freedman, Martin and Schoeni 2002). Notwithstanding this, the link between growth in disability and growth in the proportions of older people (especially amongst the ‘oldest old’, most at risk of disability) is well-recognised (World Health Organization and World Bank 2011).

The World Report on Disability estimates world disability prevalence at 15% (approx.1 billion people) for the total population, and at 38.1-46.1% for ages 60+ (World Health Organization and the World Bank 2011). It estimates that between 7% and 10% of the latter experience severe difficulty.

4.7.2 World Prevalence: Focus on Ageing with Disability (AwD)

The prevalence of AwD is unknown due to gaps in the evidence base (Sheets 2010; Verbrugge, Latham and Clarke 2017). Yet large numbers of people are known to be ageing with disability (Freedman 2014; La Plante 2014) and they sometimes experience secondary conditions and more rapid ageing (La Plante 2014) against a backdrop of social disadvantage (Iezzoni 2014).

Estimates of populations that isolate age of onset prior to mid-life come from the U.S.: approximately 30-40% of the disabled adult population had an onset at/before age 44 with the remainder experiencing disability onset afterwards (Verbrugge and Yang 2002; Sheets 2010; La Plante 2014).

4.7.3 Ireland - Population Ageing, Disability Prevalence, Type and Severity

Turning to the Irish situation, I address prevalence, type and severity of disability in older age. I also look at gender and family status aspects and I refer to what is known about the prevalence of AwD.

Irish Censuses have included disability questions since 2002. Census questionnaires for 2011 and 2016 contained the same two questions. A person is considered disabled if they responded ‘yes’ to any of seven types of disability listed in question 16 *or* to any of four categories listed in question 17 on difficulties with activities (which I will list below) (Central Statistics Office 2012a). See **Appendix A**. Thus, either having a ‘condition’ or an activity limitation would qualify respondents as disabled, irrespective of age, and this reflects international approaches to the framing of disability censuses/surveys (see World Health Organization and the World Bank 2011). The disability-types listed in question 16 were:

1. blindness or a serious vision impairment,
2. deafness or a severe hearing impairment,
3. a difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying,
4. an intellectual disability,
5. a difficulty with learning, remembering or concentrating,
6. a psychological or emotional condition, and
7. a difficulty with pain, breathing or any other chronic illness or condition.

As I finalise this Chapter (August 2017), highlights from Census 2016 are available, but not full, detailed information on age-groups and disability. So, I refer to Census 2016 statistics where available, but in most cases rely on Census 2011 information. See **Table 4.2.**

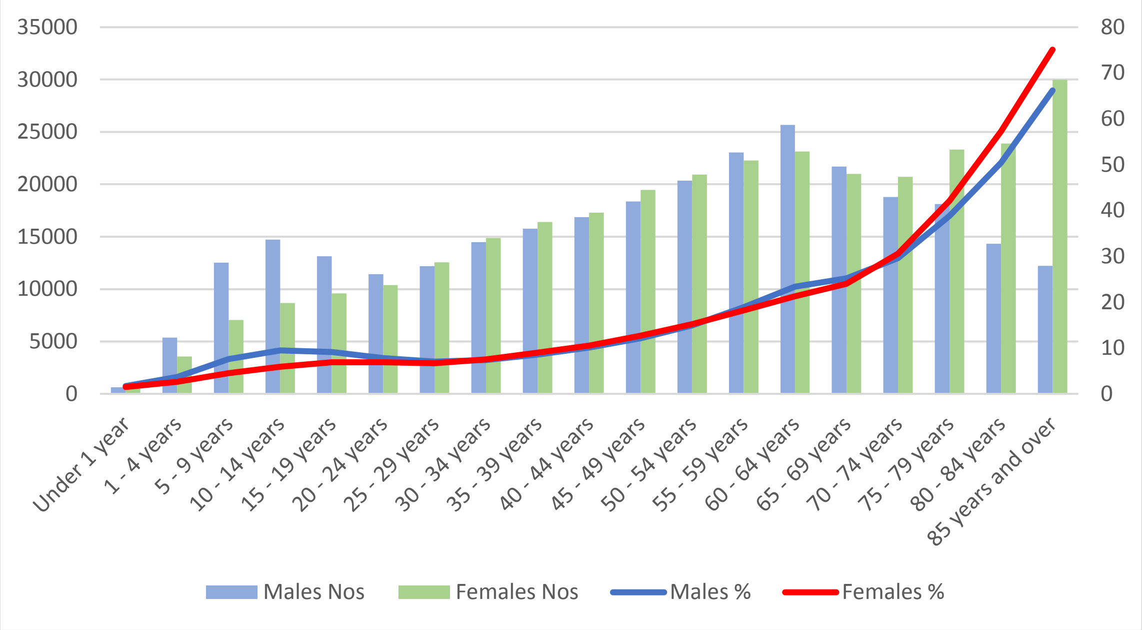
Table 4. 2 Irish Census Data: 2006, 2011, 2016. Prevalence of Disability

	2006	2011	2016	Change 2006-2016
				General Population
Total	4,239,848	4,588,252	4,761,865	+12.3%
Ages 65+	467,926 (11%)	535,393 (11.6%)	637,567 (+13%)	+169,641 (+36%)
Ages 75+	205,378	230,565	264,059	+58,681 (+28.5%)
				Disabled Population
All Ages	9.3% 393,785	13% 595,335	13.5% 643,131	+4.2 pps +249,346 (+63%)
Ages 65+	138,257 (29.5% of age group; 35% of disabled people)	204,069 (38% of age group; 34.2% of disabled people)	224,388 (35% of age group; 35% of disabled people)	+86,131 (+62.2%)
Ages 75+	84,445 (41% of age group; 21.4% of disabled people)	121,871 (53% of age group; 20% of disabled people)	130,627 (49.5% of age group; 20% of disabled people)	+46,182 (+54.6%)

Source: Censuses 2006-2016. Central Statistics Office Online Databases. CD801.CD808. CDD01. CDD02. CDR06, E9001, EY007 and Central Statistics Office 2012c (Table 1A). **2016:** Central Statistics Office 2017a;2017b.

Table 4.2 and **Figure 4.1** (below) show that the disability rate increases with age and that older disabled people make up a large proportion of disabled people. Thus, in 2016, over 220,000 people aged 65+ were disabled, representing 35% of the age group and also 35% of the disabled population. Their numbers had increased by more than 60% since 2006.

Figure 4. 1 Number/Percentage of Disabled People by Age and Gender



Source: Census 2011: Central Statistics Office Online Database. CD801. Shows numbers of people with disabilities and percentage within each age group

Census data shows disability types commonly experienced in older age and the activity and participation limitations they experience. Rates tend to increase at age 75. **Figure 4.2** illustrates this based on the seven disability types used in Census 2011 (respondants could tick more than one type).

Disability-types most commonly reported by those aged 65+ were mobility conditions,[30] followed by ‘other’ (characterised as ‘other disability, including difficulty with pain, breathing or other chronic illness’), then deafness, a difficulty with learning, remembering or concentrating, and blindness (CSO online database CD808). Mobility conditions increase gradually at first and more rapidly from about age 60, and especially from age 75. Deafness and blindness increase most rapidly after age 75, blindness especially from age 85.

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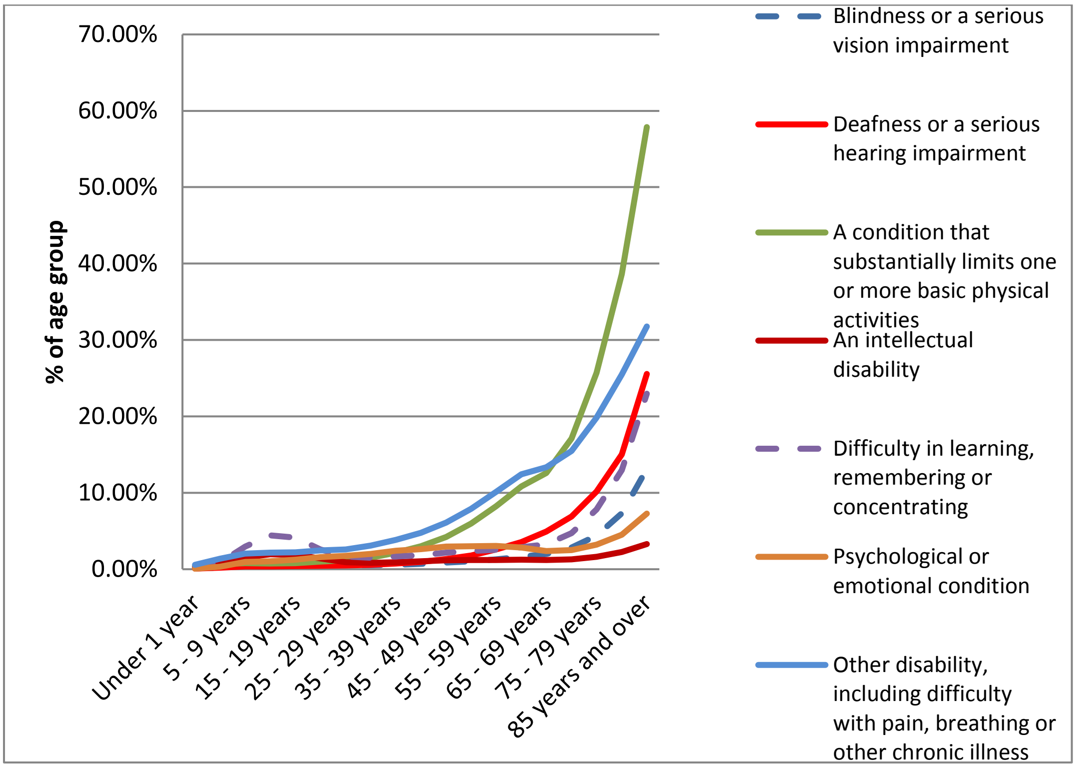
[30] Or ‘a condition that substantially limits one or more basic physical activities,’ as the Census questionnaire puts it.

Figure 4. 2 Disability Type by Percentage of Age Group (Census 2011)



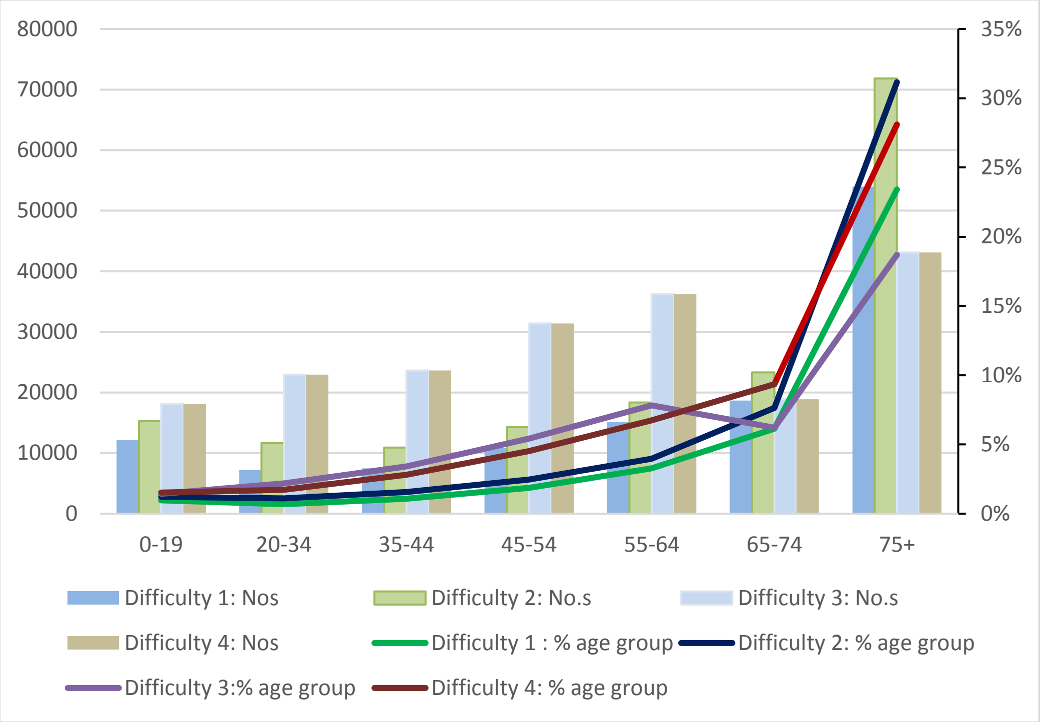
Source: Census 2011: Calculated from Central Statistics Office Online database CD808

Turning now to activity and participation limitations, as mentioned, question 17 of the Census questionnaire captured information on four categories of difficulties with activities:

1. dressing/bathing or getting around inside the home,
2. going outside alone,
3. working or attending school/college,
4. participating in other activities (like leisure/using transport).

Experiencing these difficulties also shows a strong association with ageing, especially from age 75. The absolute number of people in different age groups experiencing these difficulties shows that more older people are affected than other age groups. For example, 31% of those aged 75+ (71,838 people) had difficulty going outside home alone (out of a total of 230,565 in this age group) whereas 1.1% of people aged between 20-34 did so (11,646 people out of a total of 1,052,298 people in this age group) (Central Statistics Office Online database CD808 and CDD09). See **Figure 4.3**.

Figure 4. 3 Number/Percentage (of age group). People with Difficulties with Activities



Source: Census 2011: Calculated from Central Statistics Office Online database CD808 and CDD09

The National Disability Survey (NDS) was a once-off survey carried out in 2006 by the Central Statistics Office intended to establish the severity and impact of disability. Unlike the Census, the NDS asked about levels of severity or difficulty experienced on a scale from ‘no difficulty’ to ‘cannot do at all’.

Overall, severity of disability experienced was greater for older people than younger, especially for those aged 75+; difficulty levels tended to be greatest amongst people with mobility/dexterity conditions (Central Statistics Office 2010; Watson and Nolan 2011).

The NDS also asked disabled respondents about social participation. One question asked about eight specific types of social activity (Central Statistics Office 2010)[31]. There was a clear pattern of older disabled people reporting greater difficulty than other age groups across all activity types. For example, 62.3% of disabled people

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[31] Going to town/shopping, going on holiday, hosting friends, visiting friends, socialising in a public venue, attending religious ceremonies, voting, taking part in community life.

aged 18-34 experienced a difficulty, but 75.1% and 89.3% did so at ages 65-74 and 75+, respectively (Central Statistics Office 2010, Detailed Table 8.6)[32].

4.7.4 Gender, Family Status and Living Alone

Feminist scholars highlight gender dimensions of disability in older age (see Arber and Ginn 1991). In Ireland, women outnumber men at older ages. The population at age 65+ is 55% female; that at age 75+ (a point where impairment rates increase) is almost 60% female, and at age 85+, the female proportion is almost 70% (CSO online database EY007). It follows that when the older disabled population is considered, women outnumber men to a greater degree. Women make up 58% of the disabled population aged 65+ and an even greater proportion (63%) at age 75+ (Census 2011: Central Statistics Office, online Database CD808).

Table 4.3 illustrates that there are also higher rates of disability amongst women than men at every age after age 70 (that is, as a proportion of their overall age group). For example, for women at ages 85+ the disability rate was 75.1%, for males, 66.2%.

Table 4. 3 Disability Prevalence in over 60s by Gender (Census 2011)

	%	%	%
Age	**Males**	**Females**	**Both Sexes**
60-64	23.4	21.3	22.3
65 - 69 years	25.2	24	24.6
70 - 74 years	29.6	30.6	30.1
75 - 79 years	38.8	42.1	40.6
80 - 84 years	50.4	57.3	54.5
85+	66.2	75.1	72.3
All ages	12.7	13.2	13

Source: Census 2011: Central Statistics Office Online Database. CD801. Relates to disabled persons as a percentage of all their age group

Family status is also relevant. Widowed women greatly outnumber widowed men amongst older disabled people. Of the 118,887 disabled women aged 65+, 60,733 (51%) were widowed and they constituted 80% of all widowed disabled people in this age group (Census 2011). The equivalent figure for men was 85,182 of whom

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[32] The rate for all ages was 72.5%

14,749 (17.3%) were widowed (representing only 20% of disabled widowed people in this age group).

It is not surprising having regard to the above that more disabled people aged 65+ live alone (in private households) (33%) than their non-disabled peers (28%) (Central Statistics Office online database CD825). Disabled older women are also far more likely to live alone than men - amongst the 56,087 disabled people aged 65+ living alone, 37,443 were women (66.8%), 18,644, men (33.2%).

Socioeconomic factors are also relevant to the interrelationship of ageing and disability (Lloyd 2012), with studies from the U.S. (Henning-Smith 2016) and Ireland (Yumiko *et al.* 2012) suggesting that the heaviest disability burden falls on those who have the weakest material and financial resources.

4.7.5 Irish Prevalence: Focus on Ageing with Disability (AwD)

Finally, I briefly turn to the AwD group for whom, as in other countries, there are few data-sources. Some 36% of disabled people are aged under 44; 63% are aged 45+, while 34% are aged 65+ (Census 2011: Calculated from Central Statistics Office Online database CD808). But because census questionnaires do not ask about age of onset, they do not tell us what proportion of older disabled people *first* experienced disability prior to age 65 (or at any other age-band).

An indicative – and very approximate - estimate can be gleaned from the National Disability Survey (NDS), as respondents were asked about the age from which they were affected/limited by disability in work participation (Central Statistics Office 2010, Table 7.1). It is possible to calculate that 37% of disabled people over 65 (and living in private households) experienced disability that affected or limited their workforce participation prior to age 65, while the remainder (63%) experienced it after age 65 (Central Statistics Office 2010, calculated from Table 7.1[33]).

4.8 Statistics: Conclusion

It is not surprising that statistics show disability rising with age given that the link between the two is often seen as ‘truistic’ and that it is the basis of the influential ‘decline and loss’ paradigm of ageing (Kennedy and Minkler 1998:757). Less

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[33] Calculated from a base of 264,600 (all ages) from one of the samples used in the NDS. Nursing home residents were not asked this question.

recognised perhaps is the extent and severity of disability experienced by older people. This, I suggest, is not well appreciated in public perceptions. A severely ‘disabled person’ is more likely to be perceived as a younger person in a wheelchair than an older person (see Walker 1981b; Abberley 1987). Thus, the wheelchair is ‘the symbol of disability’, despite how only a minority (less than 10%) of disabled people (of all ages) use one (Sapey, Stewart and Donaldson 2005:493). When older people use mobility devices, they may be walking sticks, or rollators/walking-frames as well as wheelchairs (Edwards and Jones 1998)[34] and, of course, they may also experience less visible, sensory impairments.

4.9 Discussion

In this Chapter, I reviewed approaches to ageing and disability within Irish public policies and discussed the interface (or lack of it) between the two. I included a review of the position in other countries and highlighted international examples of attempts to bridge ageing and disability programmes. Statistics I presented show high rates and levels of severity of disability in older age. This problematises both how older people are left out of debates on disability, and approaches within mainstream gerontology that de-emphasise embodiment and promote positive cultural images and ‘successful’ ageing[35] in an uncritical way. It also highlights the anomaly of totally separate policy frameworks on ageing and disability. A key question informing the review is if (or how) disability policy addresses ageing and how policy on ageing addresses disability, given that disabled people age, and that (barring premature death) most people will experience disability with ageing (Zola 1989a).

Within Irish disability policies, overall, I found that there is little acknowledgement of disability in older age (whether for the AwD or DwA groups). Within older people’s policies, I found that there is no emphasis on the AwD group. Indeed, recent public policy iterations concentrate largely on ‘independent’ older people (promoting a self-managed approach to health) and do not articulate concepts, values, aims or intended outcomes of services/supports, or indeed of society, for *any* older disabled people (DwA or AwD). Placed within an active ageing framework, this reflects

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[34] This U.K. study found that a walking stick was the most commonly used mobility aid amongst people aged 65+, though use of rollators and wheelchairs increased after age 75 (when 5% used a wheelchair, 5% a walking-frame) (Edwards and Jones 1998).

[35] Rowe and Kahn (1997:433) defined ‘successful ageing’ as including avoidance of disease and disability and maintenance of high physical and cognitive function, and this definition continues to be dominant (Bowling and Dieppe 2005).

international approaches to framing of policy for older populations influenced by active ageing (and cognate) approaches, a framing critiqued by critical gerontologists (see Lloyd 2012; Grenier 2012; Phillipson 2013). This is significant in practical terms (in relation to how services are conceived of and configured) and also insofar as public policies provide narratives that affect the public legitimacy and personal identities available to older people (Estes, Biggs and Phillipson 2003:4,67; Grenier 2012:12; Hendricks 2010).

Irish policies on disability (insofar as they are explicit on the issue) sometimes assume a seamless absorption into the aged-care sector for the AwD group, and do not address the full implications of this, such as the need for upskilling and resourcing of those working within older people’s services. Instead, the AwD group requires an active interface between respective knowledge/skills within the disability and older people’s sectors (Cooper and Bigby 2014:434), a specific public policy focus and specific strategies (Bigby 2002).

Furthermore, explicit disability policy can sometimes distinguish between those under and over age 65 and reflect ageist assumptions that the only needs of the latter are for ‘support’, not community engagement. This mirrors empirical findings that ageist assumptions and stereotypes built into ‘normal’ patterns of care for older people operate destructively when applied to the AwD group (Walker and Walker 1998:127).

One key difference between the two policy frameworks is that disability policies incorporate constructions of disability informed by social models and by human rights based approaches (though stopping short of conferring legal rights). They emphasise social needs, participation and user-direction, while policies on ageing – insofar as they address people receiving social care - are aligned to medicalised approaches. Thus, contested (and explicitly defined) concepts within the disability sector are assumed to be givens within ageing frameworks. For example, public policy on ageing shows no acknowledgement that there are important and conflicting interpretations of ‘disability’ (see Titchkosky 2000 and **Chapter 2**). In fact, the term ‘disability’ is rarely used, and (in the *National Positive Ageing Strategy*) ‘dependency’ is used as a proxy for impairment or disability, showing no awareness of ‘dependency’ as a contested notion that can be a product of (or compounded by) social arrangements.

Thus, policy-making appears to proceed on parallel lines, with neither sector demonstrating an active interface or learning from the other and some instances of each reproducing ablest or ageist assumptions, respectively. The foregoing implies the need for more exchanges between the two sectors, most obviously so as to address the needs of the AwD group. As a prerequisite for this, the two sectors would need to move towards having a common understanding of what disability is. As discussed in **Chapter 2**, I argue for a biopsychosocial understanding of disability that can include both the DwA and AwD groups within the category 'disabled', and which comprehends disability in an interactional sense (that is, as personal factors interacting with contextual ones) and which seeks to bridge social and medical approaches. This approach can highlight social constructions of disablement processes in older age.

The review I report here of Irish policies shows that, as Bigby (2008) argues, separate policy frameworks define people as *either* disabled *or* older, not both. This means that public policies underscore difference between people with different timings of disability onset – between people experiencing disability first with ageing and disabled people generally, and hence between the AwD and DwA groups. Older people's policies are more medicalised, and disability policies focus more on social interaction, participation and user-control. Furthermore, there is a gap in Irish policy around the framing of strategies for older disabled people (irrespective of timing of disability onset). I conclude that if the thrust of policy is to promote positive ageing, then work needs to be done to articulate what it means for *all* older disabled people to age positively – namely, what supports and services are required, what barriers (environmental, structural and attitudinal) need to be removed and what types of relationships and communities we need to create to foster integration.

The review of policy approaches from other countries presented in the second part of this Chapter suggests that a traditional ageing/disability dichotomy is common in public policies and is associated with anomalies and problems. However, *de facto* alignment of aged and disability social care through personalised/individualised approaches can also lead to difficulties for older service-users and for some disabled people generally. But these issues tend to be investigated either from the perspective of disability *or* ageing, not both. This means, I suggest, that bridging research is necessary for practitioners, policy makers and scholars in the two fields (as Putnam 2014 argues).

Experiences of bridging older people's and disability services (especially from the U.S.) suggest that challenges to success include obtaining sufficient resources, competing underlying logics and philosophies of the two services (that is, disability and older people's services), limited professional experience of working across different groups, and professional investment in age-segmented approaches.

This Chapter's findings reinforce the need for linkages between policy and practice, research and activism on ageing and disability. This study seeks to contribute to this goal.

4.10 Conclusion and Implications

This review points to anomalies and exclusions that separate policy approaches to disability and ageing give rise to. It also finds little evidence of an active interface or learning between the two sectors in Ireland. I showed how disability policies incorporate constructions of disability informed by social models and human rights approaches emphasising social needs, participation and user-direction, while policies on ageing are aligned to narrower medicalised approaches. However, my review of international studies, suggests that making linkages between the two is complex and that mistakes are made in attempts at integration, although there are also some successes. This highlights the need for more scrutiny of all issues involved both by researchers and policy-makers.

Implications for this study are factual and conceptual. A factual issue is that it is not clear in explicit Irish disability policies which service is responsible in practice for the AwD group at age 65. A conceptual one concerns how investment of staff in age-segmented policies can operate as a barrier to greater interfacing between disabled and older people's services (shown in studies from other countries) – something necessary not least to address ageing amongst the AwD group. These issues are explored in this study's interviews with policy-makers and service-providers (findings presented in **Chapter 6)**.

Implications for approaches to public policy include the need to clarify how disability is understood in older age and to articulate what is needed so that all older disabled people may be facilitated to age positively.

Concluding Remarks

In this Chapter I contextualised this study by focusing on how policy-making on ageing and disability proceed on separate, often parallel lines, and by discussing statistical data on the interface between ageing and disability. The findings confirm my argument in the Introduction that there is a key difference between the two policy frameworks insofar as disability policies incorporate constructions of disability informed by social models emphasising social needs and participation, whereas policies on ageing are aligned to medicalised approaches. In **Chapter 6** I present findings that explore some of the implications of the foregoing within policy-making, service provision and advocacy in the separate fields of disability and ageing in Ireland. In the next Chapter, I present the methodology for this study.

CHAPTER 5 – THE RESEARCH STUDY: METHODOLOGY AND METHODS

5.1 Introduction

In this **Chapter**, I set out the study's empirical research design, including its methodology, methods and analysis.

I used biographical narrative and a constructivist grounded theory method that assumes that researchers engage in an interpretive portrayal of the studied world not an exact picture of it (Charmaz 2014). I present an overview of the overarching, conceptual categories identified in the study and the linkages between them; these form the basis for the findings Chapters that follow. This Chapter has three parts:

(1) methodology,
(2) methods, and
(4) analysis and identification of categories.

5.2 Methodology

Because an objective of this study was to explore experiences and meanings made of disablement processes, I chose a biographical method and an inductive constructivist grounded theory method.

5.2.1 Biographical Narrative

Biography can provide 'a window on the social world' (Priestley 2003a:31). Priestley (2003a:31) suggests that the life accounts of disabled people have been important to developing disability studies, because they reveal how disabling societies work and how people can challenge them. However, as I argued in **Chapter 3**, accounts of disabled *older* people are largely absent from disability studies.

Biographical research is concerned both with personal experience *and* 'externalities impinging on individuals and collectivities' (Chamberlayne, Bornat and Wengraf 2000:17). Narrative research is useful because assumptions and purposes that organise a life are difficult to access directly: precisely by what it assumes, narrative conveys tacit assumptions and norms of individuals and cultural groups (Wengraf 2001). This is compatible with a social constructionist approach to the lifecourse, which involves attempting to show how the realities of life change are accomplished and how people *constitute* the life course (Holstein and Gubrium 2000).

Thus, I chose a biographical narrative as a method that could (amongst other things) focus on how participants make sense of events and actions in their lives, to empower them to co-determine important issues, and to illuminate the impact of social structures on them (Elliott 2005).

5.2.2 Constructivist Grounded Theory

One strength of qualitative research is its ability to explicate the meaning of something from the viewpoint of the actors involved (Gubrium and Sankar 1994:x; Denzin and Lincoln 2000:3). A grounded theory method fits with the research questions of this study, because it is suited to attempts to understand the process by which actors construct meaning out of intersubjective experience (Suddaby 2006:634).

As Glaser and Strauss (1967) articulated it, the goal of grounded theory is to develop an explanatory theory of basic social processes, studied in the environments in which they take place by paying attention to the contrast between 'the daily realities' and the interpretations of those realities made by those who participate in them. Charmaz has taken grounded theory from its development by Glaser and Strauss, and its reformulation by Strauss with Corbin, to what she terms a constructivist approach (Charmaz, 2000, 2006, 2014; Silverman 2010), offering a straightforward definition:

> Grounded theory serves as a way to learn about the worlds we study and a method for developing theories to understand them (Charmaz 2014:17).

For Charmaz (2014:154,277) a constructivist approach assumes that researchers engage in an interpretive portrayal of the studied world, differing from the original approach of Glaser and Strauss. By contrast, Charmaz (2014) assumes that neither the data nor theories are *discovered* either as a given in the data or the analysis; rather we construct grounded theories through past and present involvements and interactions with people, perspectives and research practices. Thus, for Charmaz (2014:14) 'subjectivity is inseparable from social existence' and she explains that her 'constructivist' approach aligns with the form that social constructionism takes today, though she distinguishes her position from those who take a radical subjectivist stance.

This emphasis on the subjectivity of the researcher fits well with both a critical gerontological approach in which researchers reflect on their own roles in the production of knowledge (Holsten and Minkler 2007; Ziegler and Scharf 2014:158) and with a constructionist approach to the lifecourse, which requires suspending prior assumptions so as to attempt to make visible how the realities of life-change are accomplished (Holstein and Gubrium 2000: 26,47,184).

Charmaz (2014:15) allows for a flexible approach to address different research questions, and outlines the following steps pursued by grounded theorists:

1. Conduct data collection and analysis simultaneously in an iterative process,
2. Analyse actions and processes rather than themes and structure,
3. Use comparative methods,
4. Draw on data to develop new conceptual categories,
5. Develop inductive abstract analytic categories through systematic data analysis,
6. Emphasize theory construction rather than description or application of current theories,
7. Engage in theoretical sampling,
8. Search for variation in the studied categories or process,
9. Pursue developing a category rather than covering a specific empirical topic.

She views actions 1 to 5 as ‘evidence of a grounded theory study’ rather than evidence of grounded theory. Thus, I characterise my approach as a grounded theory study/approach rather than grounded theory. My study with older people meets all but item 7 of the above criteria (theoretical sampling) which was very limited in my study.

In grounded theory initial sampling is purposive (Charmaz 2006; Bowen 2006; Birks and Mills 2011). I sought to interview older people mainly drawn from two categories – those experiencing disability with ageing (DwA) and ageing with disability (AwD). I set these categories up to enable comparison between groups whose experiences are generally thought to be different. Emphasising these categories meant a sampling process that was more purposive than theoretical.

At one stage I conducted second interviews with three disabled participants – this was partly to judge the desirability of conducting second interviews generally and to explore emerging theoretical concerns. In the event, I decided to continue with a single interview with most participants. I did this because I felt confident that even a single interview was obtaining rich, substantial and relevant data (terms from Charmaz:2014:32) and I had also observed that in the AwD category, especially, participants were heterogeneous and I wished to maximise rather than narrow the numbers in that category in the time available. In effect, this amounted to sampling for range – identifying sub-categories and seeking to include a number of people within the sub-category (Small 2009). For all of these reasons I cannot claim to have engaged in theoretical sampling nor, consequently, in grounded theory, but rather in a grounded theory study (as the two are distinguished by Charmaz 2014; see above).

All of this brings me to the methods used in the research.

5.3. Methods: Piloting, Recruitment, Interviewing and Other Issues

As already discussed in the Introduction, the study's main aim is to explore subjective experiences of disabled older people focusing on physical and sensory disability and on the experience of those living at home in Ireland. The study was sequential in design, involving different types of interviews to facilitate contextualisation. To recap, the main research questions (for interviews with older people) were:

- How do older people experience disablement processes and what meanings do they make of those experiences?
- How do disabled older people respond to the challenges involved?
- Are the social processes experienced by those experiencing disability with ageing different from those ageing with disability?

For interviews with policy-makers, service-providers and representative groups the research questions were:

- How does the chronological boundary of age 65 operate between services for disabled people and older people in practice?
- How do people working in these fields relate to this separate organisation of services? and
- What are the implications for disabled older people?

In line with a constructivist grounded theory method, this study did not at the outset seek to test or flesh out any existing theories or notions of the concept of disability or of other similar or related concepts but rather it took an inductive approach.

5.3.1 Piloting and Initial Approach

Before starting the main interviews, I consulted three people experiencing disability from my personal network – a man and woman in their 80s (DwA) and a woman in her 60s (AwD). I sought feedback from them on the proposed study in general and on the content/format of the information leaflet and interview approach. They suggested no changes to the approach or to the information leaflets. I carried out pilot interviews with two of them and I learned from that about my approach to interviewing, which I will explain below.

5.3.2 Disability-type and Threshold Considerations

I focused on those living in their own homes and communities rather than in residential settings, a choice made in part for practical reasons related to gaining access to participants. I focused on physical and sensory disability for conceptual and practical reasons:

- there is no one experience of disability and not all disabled people understand one another's experience (Barnes and Mercer 2006; Shakespeare 2006); thus, the net might be cast too widely if all types of disability were represented;
- rates of physical disability and sensory disability are amongst those that increase most with age, and physical disability is the most common type of disability experienced by disabled people aged 65+.[36] (According to Census 2011 and as outlined in **Chapter 4**);
- the experience of physical disability is particularly neglected in research into ageing with disability (Bishop and Hobson 2015) and the area of sensory disability is most neglected of all (Simcock 2017);
- in practical terms, the division made sense because (1) in Ireland services are traditionally organised around client groups, one being people with physical/sensory disability (Conroy and Mangan 2006), and (2) to include people drawn from some other groups (like those affected by Intellectual Disability or dementia) would have required obtaining specialised communication skills.

I did not consider the exact nature of the disability (such as its cause) important. This was because I specifically sought to get away from medical-model framing that 'sequesters' disabled people into diagnostic categories (Dirth and Branscombe 2017:415). However, ideally, I wanted to recruit participants with both physical and sensory (that is, visual and hearing impairment) in both the DwA and AwD groups.

Thus, participants representing the following groups were the main study-participants:

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[36] Census 2011 used the terms: 'a condition that substantially limits one or more basic physical activities', 'deafness or a serious hearing impairment', 'blindness or a serious vision impairment' and all three are amongst those that increase notably with age.

1. **Group 1 (DwA):** those who had started to experience physical or sensory disability with ageing (meaning they first experienced disability in mid or later life); and
2. **Group 2 (AwD):** those who were ageing with physical or sensory disability (meaning they first experienced disability at any time from birth to around mid-life).
3. **Group 3 (ND):** those aged over 65 not experiencing disability (ND).

Crucial to the study design was the identification of these different groups, especially the first two (DwA and AwD), intended to allow identification of commonalities and differences between their experiences using an inductive approach.

As to the sample of older people not experiencing disability (**ND**), I designed the study to include them by way of what Strauss and Corbin (1990:187) call discriminate sampling, which is done in grounded theory approaches for comparative purposes, or to 'maximize opportunities for verifying the story-line' and the relationships between categories.

When it comes to defining what is 'older', there were options. A threshold of age 65+ was most obvious and I opted for it for both groups (consistent with the approach taken in Murphy *et al.* 2007). This does not imply acceptance of the notion of age-based criteria for services nor of the administratively defined notion of age 65 as the entry-point to older age[37].

For the AwD group, a lower age threshold might have been appropriate because of secondary conditions with ageing and more rapid ageing (see Putnam and Stoever, 2007; La Plante 2014). Age thresholds used in published studies with this group differ: for example, 50+ in Cooper and Bigby (2014:422); 65+ in Bishop and Hobson (2015), self-identification as 'older' in Zarb and Oliver (1993).

I opted for the same age threshold for both groups (age 65+) for consistency between groups and because it might include people who had experience of crossing the administrative service divide, of interest because the study was *inter alia* interested in public policies in Ireland. I found it more difficult to access participants in the AwD group. Thus, in the event I also included three people

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[37] I also acknowledge the arbitrariness of age 65, as 'any categorisation of chronological age obscures the physiological, psychological and social diversity of older people' (Bowling *et al* 2005).

ageing with disability who were not aged 65 (aged, respectively, 55, 60 and 61, the youngest people in the study). This was necessary on practical grounds to complete the study in the time available. It is also justifiable on the basis that this group can experience premature ageing.

Another question was how long someone had to have experienced disability to be said to be in the AwD group, and, correspondingly, how early or late one might have experienced disability to be considered in the DwA group. The literature suggests that:

(1) AwD includes people disabled from birth or childhood and experiencing disability in early or mid-life (Naidoo, Putnam and Spindel 2012);

(2) DwA includes those who experienced mid- or late-life onset (with mid-life characterised as age 45 to 64) (Verbrugge and Yang 2002).

Empirical studies with the AwD group (see Zarb and Oliver 1993; Jeppsson-Grassman 2012; Holme 2013; Cooper and Bigby 2014; Bishop and Hobson 2015) suggested a range of possibilities as to how long someone had to experience disability to be counted in the AwD group, ranging from 3 years before age 65 (Bishop and Hobson 2015) to 40 years (Cooper and Bigby 2014).

I decided that for the AwD category, I would seek people aged 65+ who had been disabled for approximately 20 or more years before age 65 – meaning they would have first experienced disability before age 45 (or, approximately, mid-life). Correspondingly, in the other category – DwA – I included those who were over 65 but experienced disability onset at or after age 45.

5.3.3 Recruitment - Inclusion and Exclusion Criteria

In the main, the study accessed participants through disability and aged-sector organisations. I worked with:

- six separate centres/services (attached to four disability organisations), including care/resource centres and a social/interest-based organisation, and
- three older-people's organisations – two were day centres/clubs, one was a membership centre based around activities/interests.

Staff members were asked to invite men and women to participate and who met the criteria outlined below.

Criteria, DwA Group – To be included participants had to be:

1. Men or women aged 65 years or over,
2. Having long-standing disability experienced with ageing (that is, since aged 45),
3. The principal disability experienced to be of mobility or dexterity, sight or hearing (that is, one or more),
4. Living at home (alone or with family or others),
5. Cognitively and physically able to participate,
6. Able to give informed consent,
7. Willing to participate in the study**.**

By 'long-standing,' I meant needing to have lasted for 6 months or more or to reoccur regularly, in line with the Census 2011 questionnaire (Central Statistics Office 2012a; Appendix 2). In practice, participants' experiences of disability tended to be very much longer than this.

Criteria, AwD group – I used the same criteria as above save for item 2, which in this case was:

2. Experiencing one or more disability of mobility or dexterity, sight or hearing, the onset of which occurred at least 20 years prior to age 65.

Comparative ND group – As mentioned already, by way of discriminate sample for comparative purposes (Strauss and Corbin 1990:187), I recruited a small number of non-disabled participants. This group were volunteers/members of older people's groups who were identified by the same gatekeepers as not experiencing disability, who self-identified as such, and who I also so confirmed as such on the basis of the Census Questionnaire (see below). However, I found, as I analysed transcripts and compared them, that to do justice to this aspect of the comparison (that is, comparing the non-disabled group with the disabled group) would add considerable complexity to an analysis and study that was already complex. Furthermore, as I was also finding that this group was heterogeneous in a range of ways, to do justice to this comparative aspect of the study, I thought that it would be desirable to expand the numbers of participants within this sample (non-disabled). I did not consider this feasible within the time available and I also felt that the focus on the disabled participants was the core aspect of the study. All of this means that while I include some comparison with this group in **Chapter 7** (bodies), I do not otherwise discuss the analysis of their interviews.

I chose centres likely to supply diversity in terms of participants (such as urban/rural) and disability type. One of the disability centres I worked with, unusually, included clients experiencing disability onset after age 65. Another mainly supported lifelong hearing-impaired people but also ran self-support groups for those experiencing hearing-impairment after age 65. I also used personal contacts to reach a small number of others, principally to include people not involved in disability/older people's centres and, at a certain point, to recruit more men. In some cases, I met potential participants in advance of interviews (either individually or in groups); in other cases recruitment was handled entirely by gatekeepers and I met participants for the first time just prior to interviews.

5.3.4 Recruitment: Determining 'Disability'

There were several considerations in relation to how the study would determine if participants were 'disabled'. Based on my experience and the literature review I conducted, I hypothesised that AwD participants, might self-identify as 'disabled' (though that could not be taken for granted), but that the DwA group would be unlikely to. I took two approaches:

(1) accessing participants through gatekeepers who identified them as disabled, and

(2) including specific questions at the interview stage that would seek self-reported information on conditions and activity/participation limitations.

For the gatekeepers connected to the disability organisations, this issue was straightforward as they considered all their clients/members 'disabled'. Something that I did not anticipate at the outset was that participants recruited from disability organisations fell into both the AwD and DwA categories, which meant that I found it harder to recruit the AwD group and had to work with more organisations/services to do so than originally anticipated. This happened because the participants in question had experienced disability onset after midlife but prior to age 65 and had started to use a disability service in the interim[38]. Thus, they were attached to disability day centres but within the DwA category as defined by Verbrugge and Yang (2002) and as I defined it (see above).

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[38] As mentioned, there were others attending one disability centre specifically aiming to involve clients experiencing disability for the *first* time in later life (that is, even if disability was experienced after age 65): their Manager explained that his centre was one of only two centres in the country that did so, and I did not encounter any other centres that did so.

For some organisations working primarily with older people, the situation as to who was 'disabled' was sometimes more complex. While it was straightforward in some cases – where I recruited through condition-specific organisations – this wasn't always the case. For example, in an older persons' day centre, some clients/members – those using wheelchairs or walking only with the assistance of a rollator, for example - might be readily identified as 'disabled.' However, those, say, walking with a stick or experiencing a level of visual/hearing impairment might be harder to categorise as 'disabled'. In conversational pointers to help gatekeepers select, I'm afraid that I sometimes may have colluded in what Priestley (2003b:58) describes happening within older people's organisations – where only significant mobility impairments are perceived as 'real disability'.

Disability surveys typically do not rely on disability self-identification, and instead seek self-reporting on conditions and functional difficulties (United Nations Department of Economic and Social Affairs 2008; Priestley *et al.* 2016:3; Marković 2014). Partly in anticipation of these kinds of challenges, and to be able to compare experiences across the sample, I decided that I needed a systematic approach to categorisation. Thus, I added disability categorisation questions to a largely unstructured narrative interview-format (see below). I used these at the end of interviews to help confirm that participants belonged in each of my three categories (DwA, AwD and ND).

I took advice on this from a public official who had worked on definitions of disability for the Irish Censuses and for the National Disability Survey. After consulting, I decided to use the disability questions (questions 16 and 17) from the national Census 2011 (Central Statistics Office 2012a)[39]. Question 16 enquires about the nature of 'long-lasting conditions or difficulties' and specifies seven possible disability types that are phrased in general terms not diagnostic categories[40]. Question 17 enquires about four types of limitations to functioning[41]. See **Appendix A.** If people answered 'yes' to any of the categories in either question, they would

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[39] Identical questions were subsequently used in Census 2016 (Central Statistics Office 2017a:Appendix5).

[40] (1) Blindness or a serious vision impairment; (2) deafness or a severe hearing impairment; (3) a difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying; (4) an intellectual disability; (5) difficulty with learning, remembering or concentrating; (6) psychological or emotional condition; and (7) a difficulty with pain, breathing or any other chronic illness or condition.

[41] (1) dressing, bathing or getting around inside the home, (2) going outside the home alone to shop or visit a doctor's surgery, (3) working at a job or business or attending school or college, and (4) participating in other activities, for example, leisure or using transport.

be categorised as disabled according to the Census. I chose this categorisation approach to conform to how disability rates are calculated at a national (and supra-national) level rather than more biomedical approaches[42] and partly because they were straightforward and relatively brief. Thus, I felt I could incorporate them into the end of an otherwise largely unstructured interview without difficulty. Testing them during piloting gave me confidence about this too.

I considered severity of disability: a severely hampering chronic illness or disability impacts more significantly on social participation (Gannon and Nolan 2005; Flash Eurobarometer survey from 2012, cited in Priestley *at al*. 2016). Participants in the Irish National Disability Survey were asked a self-reported level of difficulty question on a scale. The public official I consulted advised also including a scale. This led to my decision to include a question about level of difficulty occasioned by any reported disability (from a five-point scale of ‘no difficulty’ to ‘a lot of difficulty’ and ‘cannot do at all’) alongside questions 16 and 17 from the Census 2011 questionnaire. This was the same scale used in the National Disability Survey 2006. See **Appendix B and C.** It is also used in international approaches to measurement of disability prevalence (see United Nations Washington Group on Disability Statistics 2008).

5.3.5 Recruitment: Communications

I sought to avoid using abstract language in introducing the study to gatekeepers and potential participants. Decisions had to be taken for clarity and because disability definitions are contested and none is perfect (Graby 2015; see **Chapter 2**). In the information sheet for participants, I decided on the phrase ‘long-standing condition’ for consistency with Census 2011 (question 16) (Central Statistics Office 2012) and in brackets I included reference to ‘illness,’ as well as ‘impairment’ and ‘disability’ – to supply a choice of terms that respondents might identify with. Thus, the study’s information leaflet sought:

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[42] An alternative might have asked about difficulties carrying out ADLs (activities of daily living like dressing/washing) or IADLs (Instrumental activities of daily living like preparing meals or taking medication) (see TILDA, Yumiko *et al* 2012). But using ADL/IADLs reflects a biomedical approach with a narrower focus than the questions used in the Census, which broadens out from activities at home into issues like going out alone and participating in leisure activities.

> People aged 65 or older living with a long-standing[43] condition (relating to impairment, disability or illness) that is having a noticeable effect on their lives.

See **Appendix D**, which includes the information sheets made available to potential participants, which differed slightly for each of the three groups.

5.3.6 Two Groups of Participants – Policy-Makers/Service providers/Advocacy Organisations and Older People

Because of the two aspects to this study – one with people working on disability and ageing, and one with older people - there were some differences in approach to the two. In this section I outline the characteristics of the participants drawn from both groups.

Participants – Part 1 (policy-makers and others)

I decided to conduct interviews with policy-makers, service-providers and advocacy organisations having reviewed explicit public policies (see **Chapter 4**), and in part as a strategy to connect/reconnect with people working in disability/older people's services so that they might help with recruitment of older people, a strategy that proved successful.

Table 5. 1 Participants: Policy-makers, Service Providers, Representatives of Advocacy Organisations

Area of Experience	Disability	Ageing
	N	N
1) Policy-making or advising on policy	2	2
2) Service provision focusing on social care	3	3
3) People from NGOs involved in representation/advocacy and related programme delivery	3	2
4) Person from NGO involved in advocacy whose remit crossed over the two areas of disability and ageing: N=1		

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[43] This could be explained as needing to have lasted for 6 months or more or to reoccur regularly, as per the explanatory note provided in the Census 2011 questionnaire (Central Statistics Office 2012a; Appendix A).

I conducted interviews with 16 participants. The first interview in this series took place in June 2015, the last in May 2016. See **Table 5.1.** I recruited participants who worked in ageing or disability in three areas:

(1) policy-making/ advising,
(2) management of services supporting people to live in the community, and
(3) advocacy or related activities within NGOs.

Most participants worked for statutory or non-profit organisations with a national remit. One worked for a private home-care provider. Initial sampling was purposeful; a snowball sampling process followed where informants suggested others. I prepared interview topics and made them available in advance. The Information sheet and topic guide are in **Appendix E**.

Participants – Part 2, Older People

In addition, I conducted 53 interviews with 50 older people between September 2015 and June 2017. All were community-dwelling in their homes; several lived in housing complexes for seniors or for disabled people. **Table 5.2** sets out key participant characteristics. And in **Appendix F**, I include further information about each participant, including their age, details they gave of type of impairment and severity, decade of onset, family status, and the location of their home (that is, urban/rural etc.)

Ages and Gender: The 50 participants had an age range of 55-94. Amongst the 42 disabled people in the sample, the age range was 55-90; the mean age was 74.1, the median, 72.5. Amongst the AwD group (n=18), the range was 55-90 (three were under age 65); amongst the DwA group (n=24), it was 65-88, and amongst the ND sample (n=8), it was 66-94. There were more women than men in the sample amongst the disabled group (F=25; M=17) and overall (F=32; M=18). This, I believe is justifiable. As outlined in **Chapter 2**, of the 204,069 people aged 65+ who are disabled in Ireland almost 60% (58.2%) are women, while men represent 41.7% (Census 2011, calculated from CSO online database CD801). These proportions are almost identical to those amongst my sample of disabled people (N=42: F=25 (59.5%); M=17 (40.4%).

Impairment types and Severity: The DwA group (n=24) and the AwD group (n=18) were experiencing a range of impairment types, including mobility issues, hearing and vision-impairment. As already explained, I deliberately wanted to avoid a medical framing into diagnostic categories, and instead relied on the more generic approach to categorisation used in the Census (consistent with international approaches to defining and measuring disability, as explained already). Participants' narratives referred to a range of diagnoses. I list these as they explained them in **Appendix F**. For example, mobility issues could relate to a range of conditions that included Multiple Sclerosis, amputation, stroke or arthritis. Visual impairment could also have a range of causes; it could be congenital or arise from an accident or a condition like macular degeneration. Or participants could be vague about the exact cause of a mobility or sensory issue. Some people were very clear when onset had occurred, others (especially amongst the DwA group) described gradual onset and could not say exactly when conditions started. Many were experiencing more than one disability-type, and if they reported that they did so as they answered questions from the Census, I asked them to say which caused them the most difficulty (unless that was already clear from their narratives).

A difficulty with mobility was the commonest primary type of disability identified, and a difficulty with vision, the second (33 and 6 participants, respectively). Thirty-two of the disabled participants (76% of them) identified more than one disability type. Their narratives often involved interconnecting experiences of, say mobility difficulties and pain or hearing/sight impairment, to which the list of 'primary' disability types listed in **Table 5.2** does not altogether do justice. Those in group 3 (n=8) were not experiencing disability.

As described already, I included at the end of each interview - along with the disability questions from the Irish Census - scales of difficulty questions, seeking self-reported information on level of difficulty caused. Twenty-two out of 41 participants[44] (53.6%) fall into the category of experiencing disability at the most severe level (on the basis that in at least one domain they experience 'a lot of difficulty' or 'cannot do at all'[45]). There were 11 people in this category in both DwA and AwD groups.

Other Demographic Information: Participants lived in a range of locations (cities, towns, villages and rural areas) and they were mixed in terms of family status – in

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[44] Note: one DwA participant did not complete the Census questionnaire so I do not have this information for her.

[45] In assessing severity of impairment, I did not include responses to one of the questions – about working or attending school or college - as most participants did not think this was relevant to them.

being single, married or separated/divorced. But none identified as LGBTQ. In this respect, and ethnically, they were quite homogenous, reflecting a particular demographic in Ireland at present. For example, all but one was white Irish (though several had lived abroad at some stage of their lives).

I took a pragmatic approach to categorising participants according to their socioeconomic status (SES) based on their narratives of their lives. This meant that amongst the disabled group, 15 (36%) were categorised as having low SES, 17 (40%) as having middle and 10 (24%) as having high. Thus, they reflect a range of socio-economic backgrounds. To do so I used the occupational status categorisation used by the Central Statistics Office (CSO) of Ireland (Central Statistical Office 2012c; 2012d). I re-grouped into them into three categories of high, middle and low SES based on their last occupation (adopting the approach of Timonen *et al.* 2013). Following Census guidelines, participants who had never worked were categorised to an SES category based on either their partners' SES or that of their families of origin. Again, this information is given for each participant in **Appendix F.**

Reflection on Use of Census Questions: As will be clear from the findings (especially those reported in relation to disabling contexts**, Chapter 8),** using the Census questions at the end of each interview – which asked about long-standing conditions and activity limitations - provoked some interesting responses suggesting how participants understood and experienced disability. Even though I conceived of this as an aid to classification, the answers it provoked and the interactions we had about them often proved interesting. Thus, I found that everything was data and I included these answers in my analysis.

Here, it is necessary to explain a little about this to clarify how some participants have been categorised. As outlined above, relative to two questions from the Census questionnaire, if anyone answers 'yes' to either question (the first about the nature of 'long-lasting conditions or difficulties'; the second about four types of limitations to functioning) they are classified as 'disabled'. All of those I categorised as disabled answered 'yes' to the first question – thus, they would be 'disabled' according to the Census criteria. However, categorisation was not straightforward in all cases:

Non-disabled?: Some of those who had been recruited as 'non-disabled' (identified by gatekeepers and by themselves as 'non-disabled') also answered 'yes' to the first disability question. In other words, they had a condition (like hearing impairment or asthma), and thus would be 'disabled' according to the Census. Some even had two conditions. However, if they considered these conditions to cause them 'no difficulty' – I categorised them as 'non-disabled'.

Disabled? The obverse of this issue occurred in respect of some of those recruited as 'disabled'. All identified as having a 'condition' and thus would be 'disabled' according to Census criteria. But a small number felt that their impairments caused them no difficulty and answered 'no' to all the questions about limitations in functioning, as they did not feel 'limited' in the way they functioned - or at least not in the ways that the Census envisages. Sometimes they felt that impairment did cause some difficulty in their lives, but in none of the ways that the Census envisages. This group included lifelong visually-impaired people and one wheelchair-user since childhood. If I had followed the logic I had followed with the 'non-disabled' sample, I would have categorised them as 'non-disabled'. Instead, I categorised them as 'disabled' which I recognise as somewhat inconsistent – but the alternative – to categorise them as non-disabled was more problematic[46].

These issues are relevant to the findings of this study as to how disability was experienced and understood, and I will discuss them again. They also illustrate the subjective and contextual, not organismic, nature of disability and the complex category of disability itself, which, as Davis (1995:11) describes it, is based on a deconstruction of a continuum.

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[46] For example, for conditions such as blindness, a severe level of disability is inferred in the World Disability Report (World Health Organization and World Bank 2011).

Table 5. 2 Older Participants: Key Features

		Disability with Ageing (DwA): onset after age 45 N=24		**Ageing with Disability (AwD): onset before age 45** N=18		**All Disabled Participants** N=42	**Not Disabled (ND)** N=8		**All Participants** N=50	
Sex	**Males**	12		5		17	1			18
	Females	12		13		25	7			32
	total		**24**		**18**	**42**		**8**		**50**
Age	**50s**	0		1		1	0			1
	60s	8		9		17	1			18
	70s	8		3		11	4			15
	80s	8		4		12	2			14
	90s	0		1		1	1			2
	Age range		65-88		55-90	55-90			66-94	55-94
Family status										
	single	4		7		11		1		12
	married	11		3		14		0		14
	widowed	6		5		11		6		17
	separated/ divorced	3		3		6		1		7
Locations										
	City	14		11		25		4		29
	Town	2		2		4		0		4
	Village	4		2		6		1		7
	Rural	4		3		7		3		10
Disability type - primary[1]									n/a	
	Mobility	19		14		33				
	Vision	2		4		6				
	Hearing[2]	1		0		1				
	Other[3]	2		0		2				
Highest Level of Disability Severity (self-reported level of difficulty)[4]									n/a	
	No difficulty	1		3		4				
	Just a little	4		1		5				
	Moderate level	7		3		10				
	A lot of difficulty	5		3		8				
	Cannot do at all	6		8		14				

[1] 32 of the 42 disabled participants identified more than one disability type.

[2] No lifelong deaf person participated; one DwA participant (recruited through a lip-reading organisation) characterised his primary disability-type as 'other' relating to an earlier diagnosis of cancer, and ‘hearing’ as a secondary condition, though much of his narrative involved challenges of hearing impairment.

[3] Two participants opted for 'other' relative to their primary disability: (1) one DwA participant opted to describe hers as a psychological condition and mobility as a secondary condition, and (2) see previous footnote (2).

[4] One participant did not complete this questionnaire and died before a second interview was arranged.

5.3.7 Recruitment: Challenges

Recruitment through gatekeepers often involved engaging at a senior level with a national organisation followed by liaison with managers of individual services. There were some challenges, but overall this was very successful; several managers were enthusiastic about the study and some provided feedback that their clients enjoyed participating.

The main challenge was the length of time it took from first contact to starting interviews. In one case, I first contacted a disability organisation 6 months before I got to interview one of their clients. Their initial estimate that they might have 10 people meeting the criteria (for the AwD group) proved over-optimistic and, ultimately, this service only had two people who met the criteria and wished to participate. Thus, accessing sufficient numbers within the AwD category, especially, was challenging.

Another challenge related to recruitment of lifelong deaf people – whom I wished to recruit so as to include experiences of this impairment type amongst both the AwD and DwA groups. I worked for some months with an organisation supporting deaf people and recruited people experiencing hearing-impairment with ageing. However, despite some initial interest, no lifelong deaf person agreed to participate. The organisation involved suggested that this related to references to 'disability' in the title of my study, as deaf people (or sign-language users) consider themselves not disabled but a linguistic subgroup (Davis 1995; Garland-Thomson 2016). While I modified the information somewhat on the advice of this organisation, I could do so only to an extent without being duplicitous about the nature of the study.

A further issue that could make recruitment challenging was that gatekeepers found the recruitment criteria complex, particularly the ceiling for age of disability onset of age 45 for the AwD group (see Verbrugge and Yang 2002). They were not always sure when onset had occurred or not without checking records. On several occasions I had understood that an interviewee belonged in one category but, during interviewing, as they talked about the timing of disability onset, I found that their accounts suggested that they fitted into the other – and in a small number of cases it was difficult to decide which one they fitted into[47]. This shows the somewhat

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[47] Such as one man who had a 'short' leg since he was a toddler, but who went to a mainstream school, and worked until a standard retirement age of 65. He had not engaged with disability services – I recruited him through a centre for older people. But, in the event I

artificial or stereotypic nature of the distinction between the two groups and the complex nature of disability as a category. As Koch (2004) puts it, an either/or paradigm in which one is ‘normal’ or ‘disabled’ is inadequate to conceptualise the diversity involved, even across an individual lifecourse. And attempts at categorisation are somewhat crude, given age and disability are not defining traits of an individual, but overlapping phenomena that occur throughout the lifespan (Verbrugge and Yang, 2002:253; Naidoo, Putnam and Spindel 2012).

This meant that I was not always in control of recruitment between the two groups and, in practical terms, that I recruited fewer males than females in the AwD category. To have tried to have made the numbers more equal in both categories would have required a much longer field-work stage. While I recognise that the small number of males in the AwD group is a limitation, I also believe that having more women in the study than men overall is justifiable and is supported by the demographic information in **Chapter 4.**

Finally, there was one participant, interviewed in a disability centre, who came late to the appointment and whose interview came to a slightly rushed end (when her bus arrived) before I got to ask her the Census categorisation questions. We agreed that I would reschedule but, unfortunately, this participant died shortly afterwards and before I could do so. It means that I do not have her self-report of disability based on the Census questions.

5.3.8 Interviews

Intensive interviewing is the most typical approach to interviews used by grounded theorists (Charmaz 2014:85). I took two different approaches to interviewing reflecting the sequential study design. I discuss here mainly interviews with older people but first briefly address the approach taken in interviews with policy-makers and others.

Interviews with policy-makers and others: An aim at the outset was to obtain information (for example, about whether disability or older people’s services were responsible for the AwD group). My approach here was clearly not biographical and I conducted semi-structured interviews, intended both to enable asking similar

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characterised him as in the AwD group because of the importance *he* attached to his condition during his life-story narrative – in particular, how he had always been self-conscious about it and perceived it as having prevented him from having had relationships with women.

questions across interviews, to facilitate both comparison and flexibility (Bernard and Ryan 2010). In the event, the interview process went beyond the elicitation of facts as **Chapter 6** will discuss.

Interviews with older people: Following pilot interviews, I used an open-ended or narrative interview (also called unstructured interactive interviews) (Corbin and Morse 2003) and ended interviews with the disability and functioning questions from the Irish Census (see above). I interviewed people in disability/older people's centres or, where they preferred, in their homes.

Pilot and Training: For pilot interviews I used an interview guide and followed the approach outlined by Charmaz (2014) in a number of respects (by, for example, including open ended questions like 'tell me about' and probes such as 'could you describe….further?'). After piloting this approach (listening back and transcribing), I felt that participants' flow was affected by the guide. Though I knew the pilot interviewees in advance, I sensed that rapport would have been better if they had had more control – deciding, for example, where to start the narrative, what topics to include and the amount of detail to share. I felt that a narrative interview in which the participant is enabled to tell a story would work better.

Before undertaking further interviews, I undertook training in a biographical narrative method of interviewing: the Biographic-Narrative Interview Method (or BNIM) approach, which starts with a single initial narrative question focused on the biography of the interviewee (Wengraf 2001). In the BNIM method, the interviewer asks the participant to tell the story and then listens without interruption. The participant is encouraged, by attentive listening, to keep talking until they have no more to say. Agreement is gained that the interviewer will take written notes (and audio recording) and that the interviewer will ask questions based on the written notes after the participant has finished speaking. Questions are based on something the interviewee has mentioned and seek further story or narrative details.[48] Having undertaken training in BNIM, I felt that an open-ended opening question would help

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[48] I did not think it would be practical to follow a full BNIM process. Space constraints do not permit inclusion of a full discussion of these reflections. The approach involves a three-stage interview process with a requirement for a break between sub-session one and two to make notes. See Hughes (2011) who used BNIM in interviewing people aged 75+ with cancer but outlined a range of ways he varied it; including how it found it impossible to break between sub-sessions 1 and 2 in people's homes. My reasons for not pursuing the full method included practical reasons such as this.

build rapport in the early part of the interview and enable me to afterwards raise or focus in on matters that might be sensitive for the participants – such as impact of impairment on life or thoughts about the future.

Interviews in General: Following piloting and training, I started interviews using the opening question:

> ‘Please tell me your life story including life nowadays, starting wherever you like’.

I would listen without interruption until the person stopped and then ask story or narrative questions based on participants’ stories using their words. I often followed with additional questions. As time went on, I dropped the addition of ‘including life nowadays’ to the opening question, as I did not think it added to the quality of interviews. Towards the end of interviews, I checked if participants were happy to answer questions on disability from the Irish Census. All agreed.

As I became more comfortable with interviewing, I learned for myself what I’d read in the literature on interviewing - that the most important thing in terms of hearing how people made sense of their lives was to build up trust or rapport (Gubrium and Sanker 1994; Kaufman 1994b; Charmaz 2014).

5.3.9 Ethical Issues

Because some of the participants could be characterised as vulnerable, the ethical approval process was rigorous. I obtained ethical clearance from the relevant Maynooth University Ethics committee. I also undertook an additional ethical approval process required by one disability organisation.

In some cases, I met potential participants in advance of interviews (which was my preference in relation to the older participants); in others I met participants first just prior to interviews. I gave or sent participants written information in advance. (See **Appendices D** and **E**).

In all cases, I checked that participants had read the information sheet before each interview (or were otherwise familiar with the contents[49]) and whether they had any

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[49] For example, some visually impaired people described how a carer or relative had read it to them.

questions. I checked that they were comfortable with being recorded. Interviewees signed consent forms except in a small number of cases of visually impaired participants, where I recorded the consent process (something anticipated in the relevant ethical approval). I listened back to tapes, did some transcription myself and had the rest professionally transcribed. I gave pseudonyms to participants and removed other identifying information.

I was very aware that interviews might touch on difficult and emotional issues and I took a range of steps to address this. I discussed this with gatekeepers in advance and asked them to check in with participants after interviews. I also researched information on support/counselling which I had available for participants, although I never used it. In practice, what I found worked was remembering that the interests of the participants came first at all stages. For example, I took time at the outset of each interview to explain about confidentiality and my use of an audio-recorder, and to ensure that participants understood what they were consenting to, and that they knew they could stop or withdraw at any time. I let them decide what to talk about at the outset of interviews (and how long to talk about it) using an open first question as part of the interview method described already. I allowed plenty of time for each interview so that participants did not feel rushed. I was sensitive to signs of stress and I was empathic when people did get upset expressed through attentive listening and expressions of sympathy. When that happened, I checked to see if they wanted to continue or take a break. I made sure to stay with people until they recovered, and in all cases the distress evoked by their narratives appeared to be transitory and there was no sign of residual emotional discomfort at the end of interviews.

Overall, I found that participants wanted to tell their stories – even when that could be difficult for them. Several said afterwards that they had enjoyed the experience – even people who had become emotional during interviews or who had narratives with difficult aspects to them.

5.4. Data Analysis

In this section, I move on to present how I analysed the data. I took a constructivist approach to data analysis involving flexible analytic guidelines for data collection, stages of analysis, and conceptual development (Charmaz 2014). For the sake of clarity, I will focus here on the categories I identified in my analysis of interviews with older people, and address the categories identified from interviews with policy-makers and others in the next Chapter. The approach to analysis that I undertook was similar in both studies.

A grounded theory analysis requires two criteria – fit and relevance (Charmaz 2014:133); fit involves constructing codes and developing them into categories, while relevance involves offering an ‘incisive analytic framework that interprets what is happening and makes relationships between implicit processes and structures visible’. Codes are short labels used to depict what is happening in a piece of data. Coding defines what is happening and links collecting data with developing an emergent theory to explain the data: initial coding is followed by a focused, selective phase that uses the initial codes to synthesize and organise large amounts of data (Charmaz 2014)[50].

5.4.1 Initial Coding

I started initial coding and comparison soon after I started interviewing and I continued to code as I interviewed. I engaged in constant comparison to find similarities and differences – especially statements and incidents in different interviews (Charmaz 2014:132). I used a software programme (MAXQDA) to organise the analysis.

From interviews with older people, open coding resulted in hundreds of different sub codes and over 5,200 coded segments. See **Appendix G** for examples of initial coding and how some initial codes were incorporated in sub-categories and main categories.

I listened back to recordings and read and reread transcripts. I made memos during all stages of the analysis, including immediately after each interview and immediately after I coded each new transcript, when I also considered similarities and differences in each case.

5.4.2 Focused Coding

The analysis process is not a linear one. But stated in linear terms, another stage in a constructivist analysis is focused coding requiring ‘decisions about which initial codes make most analytic sense’ thinking about the ones that may be promising

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[50] This is a variation of classic grounded theory involving a three stage process of analysis: open, axial, and selective coding (Strauss and Corbin, 1998).

‘tentative categories’ (Charmaz 2014:138,140). For me this stage was about assessing the initial codes and the comparisons made between them and deciding which ones were core to the analysis.

Charmaz (2014:140) advises to ‘keep your involvement in mind as you proceed’. I tried to follow this advice through the analysis process. It proved useful, as these reflections could contribute to the development of categories or to a slightly higher level of abstraction. For example, in **Table 5.3,** I include an extract from a memo I made following coding Kathleen’s transcript showing how I developed one category - disabling contexts (discussed in **Chapter 8**).

I worked with a range of potential categories, amongst them one I called: ‘Constraint and narrowing of life is met with efforts to connect and towards continuity’. This later informed what I identified as the overarching category ‘Seeking to Remake Lives that Make Sense’ (see below). I include an extract showing how memo-writing, and trying to bracket off my own preconceptions, helped me to arrive at it. See **Table 5.4** For me this provided a deeper, more analytic explanation of what I had coded – making it explicit what I had understood but had not before conceptualised. This can be said to be an instance of abduction (Pierce 1878/1958 cited in Timmermans and Tavory 2012; Charmaz 2014). For Charmaz (2014) grounded theory begins with inductive analyses but involves abductive logic to engage in imaginative thinking about intriguing findings.

For reasons already explained, it is more correct to characterise my sampling strategy as purposive rather than theoretical. However, as my analysis focused on theory development over time, I was able to pursue some of my ‘analytic direction’ (Charmaz 2014:99) with subsequent interviewees. For Charmaz (2014:231), interpretive approaches aim to understand meanings and actions and how people construct them – they bring in the subjectivity of the actor and may recognise the subjectivity of the researcher – they assume emergent, multiple realities, and offer ‘an imaginative theoretical interpretation that makes sense of the studied phenomenon’. Thus, the emphasis is on theorising as a *practice* rather than on development of explanatory ‘theory’.

I know that it is commonplace to claim that theoretical saturation occurred in grounded theory studies (Suddaby 2006), and I feel that I may have reached it in this study – in the sense of repetition of information and confirmation of existing conceptual categories – but I am reluctant to definitively claim it, given that I did not pursue theoretical sampling to any extent and that saturation is not always obvious even to experienced researchers (Suddaby 2006:639).

Table 5. 3 Sample Memo Illustrating Development of a Main Category

Moving toward identifying the category 'Disabling Contexts'	
Extract from my Journal:	Related Extract from Kathleen's Narrative (about one of the Census questions):
As she experiences it, she has no difficulty leaving the house using taxis ('taxi[s] all the time'), something she'd said several times. I continued a line of questioning here related to using the buses after Kathleen said she no longer used them. She has no difficulty getting out of the house *because* she has the resources to pay for a taxi, but instead of accepting that answer and moving on I asked her to speculate about what it *might* be like to use public buses, which she eventually acknowledges would cause her some difficulty. I am operating from an essentialist or medicalised understanding of her impairment or functioning here – I was trying to understand what it *might* be like for her to use the buses, whereas from her perspective that isn't relevant– she feels that she has no difficulty getting out *because* she can get taxis (*taxis all the time*). Thus, her understanding of her functioning is related to her resources and her ability to take taxis not the theoretical question of whether she could use a bus if she had to.	Interviewer: You said you don't use the buses? Kathleen (DwA): I don't use the bus, no. Interviewer: OK. So you would have difficulty probably using the buses so? Kathleen: Well, I don't think I'd like to be back using the buses again. Interviewer: You don't have to? Kathleen: I don't have to. Interviewer: OK. So it would cause you some difficulty if you had to? Kathleen: Well, I think it might, yeah.

Table 5. 4 Sample Memo Illustrating Development of Overarching Category

Extract from Memo (28 July 2016) comparing cases
As I coded Josephine's transcript I started to think that the way I was looking at this was initially too negative – perhaps influenced by the first few people I interviewed or by my own sense that disability in older age must be experienced very negatively. But there is also a lot of enjoyment, an appetite for new things even amongst people who feel that they do not have much time left, and whose conditions are disimproving (e.g. Josephine talking about not seeing the faces on TV as clearly as she used to). So even faced with 'decline' there is effort, enjoyment, fun and perceived improvement in some respects. (She perceives her 'dropped leg' to be improving). So it's important to see – as a researcher – that it's not all decline – there is renewal in the teeth of decline – and there is more potential for it if people were not so confined to home (e.g. Tony). Even though Colin really regrets loss of being able to do things – go places, exhibitions, readings – he still enjoys what he can – vibrating to music and doing the washing up. He is creative in response to loss – taking photos and keeping a diary in hospital before his sight deteriorated more.

5.4.3 Development of Categories

I now come to outline the analytical concepts or categories that I identified following initial and focused coding. Categorising involves selecting certain codes as having 'overriding significance' or synthesizing patterns in several codes into an analytical category (Charmaz 2014:341). Ultimately, I felt that all the open codes could be encompassed into three main categories:

1. **Category 1:** Disabling Bodies
2. **Category 2:** Disabling/Enabling Contexts
3. **Category 3**: Responding to Challenges.

The overarching concept that encompasses the three is '**Seeking to re-make Lives that Make Sense'** which I believe 'renders the data most effectively' (Charmaz 2014:247). At the end of this Chapter, in **Figure 5.1,** I include a diagram indicating how the categories are linked

The first two categories address the research questions as to experiences of and meanings made of disablement processes, suggesting that for most participants both were understood at a bodily level *and* as the body interacts with and is impacted upon by a range of contextual factors. The third, 'Responding to Challenges', deals with how participants responded to challenges of disablement and often the simultaneous loss of intimates by trying to remake a sense of value, coherence, and ultimately meaning in their lives.

Efforts participants made to cope with disablement processes included bracketing off the impact of impairment so that the effects on identity were minimised. These and other efforts to cope represent seeking to make their lives comprehensible and to live lives they value and have meaning. Furthermore, participants often reflexively responded by maintaining existing activities and participation outlets and sometimes sought other activities and participation opportunities, and they could try and forge new contacts and relationships. In this, I argue that they are involved in an endeavour that requires a lot effort and that is little recognised. This is particularly so in a society that frames meaning for elders as 'trivial' (Edmondson 2015). This goes further than trying to maintain capacity to do everyday activities to stay alive, to maintain activities necessary to independent living (though these are important) and amounts to nothing less than being involved in a constant and dynamic process of reinterpretation and of reorienting towards meaningful lives in the face of fundamental, ongoing challenges.

Thus, the story of the data I identified (encompassed in the three main categories) was that processes of disablement and (often) the simultaneous loss of intimates and shrinking social circles could create a sense that life was less meaningful, and participants were engaged in a process of responding by **seeking to remake lives that make sense**. To be engaged in meaning-making processes is part of being human[51], but cumulative losses meant that reestablishing a sense of meaning in life became a necessity for study participants.

Participants were sometimes frustrated in their efforts for personal reasons (such as severe impairment) or contextual reasons (such as lack of suitable transport or engagement opportunities). Those who succeeded in their efforts were often helped by public policies (providing them with specific opportunities) and/or community organisations (community groups that welcomed and facilitated involvement). Having family connects and support could also be important.

All of this is true whether participants experienced disability onset for the first time in later life or experienced late-life impairments/conditions on top of existing impairments/conditions.

Overall, the findings of this study show how participants were engaged in trying to remake their lives as meaningful, which is no less a process than declaring their own worthiness ‘in the face of irreversible physical decline’ (Cruikshank 2003:23) and in the face of societally created barriers to participation and discrediting attitudes. These findings support the argument of Baars (2010:177) that the meaning of human ageing may be found in ‘a radicalization of the vulnerability of unique human life, which is not the monopoly of ‘aged’ people, but inherent to the inter-human condition’. In this process participants were dealing with existential challenges that were the inevitable results of senesce and finitude, and contingent challenges that are social in origin and can be alleviated (Settersten and Trauten 2009).

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[51] I do not mean ‘meaning’ in a cosmic sense, but, as Holstein (2015:119) says, the abiding importance of meaning to all human life and how we think about it in everyday terms. I will discuss what I do mean by meaning in **Chapter 9**.

5.4.4 Credibility

This research has attempted to meet requirements for rigor or quality, reliability, and validity that are crucial in establishing that research is credible. Trustworthiness and authenticity are the criteria for 'goodness or quality' in social constructionist, qualitative research, suggesting that the question to ask is whether the studied situation been rendered as faithfully as possible in all its complexity (Lincoln, Lynham and Guba 2018). In terms of reliability, Silverman (2011:360) points to the importance of describing the research strategy and data analysis methods 'in a sufficiently detailed manner' and, also, to the importance of 'theoretical transparency'. In the detailed sections, above, and in the Chapters to come, every effort has been made to achieve these standards. In the Chapters that follow, I will present extracts from the data and will summarise some of the data and its context where it is more appropriate (for reasons of concision and because of digressive passages in some interviews).

5.4.5 Limitations

The different categories that I set up at the outset were perhaps both a strength and a limitation: inevitably there are smaller numbers of representative interviewees in each category than there might otherwise have been. The limitations of this are particularly obvious for one category (AwD), given that participants were so diverse. On the other hand, they enabled me to explore similarities and differences between the groups.

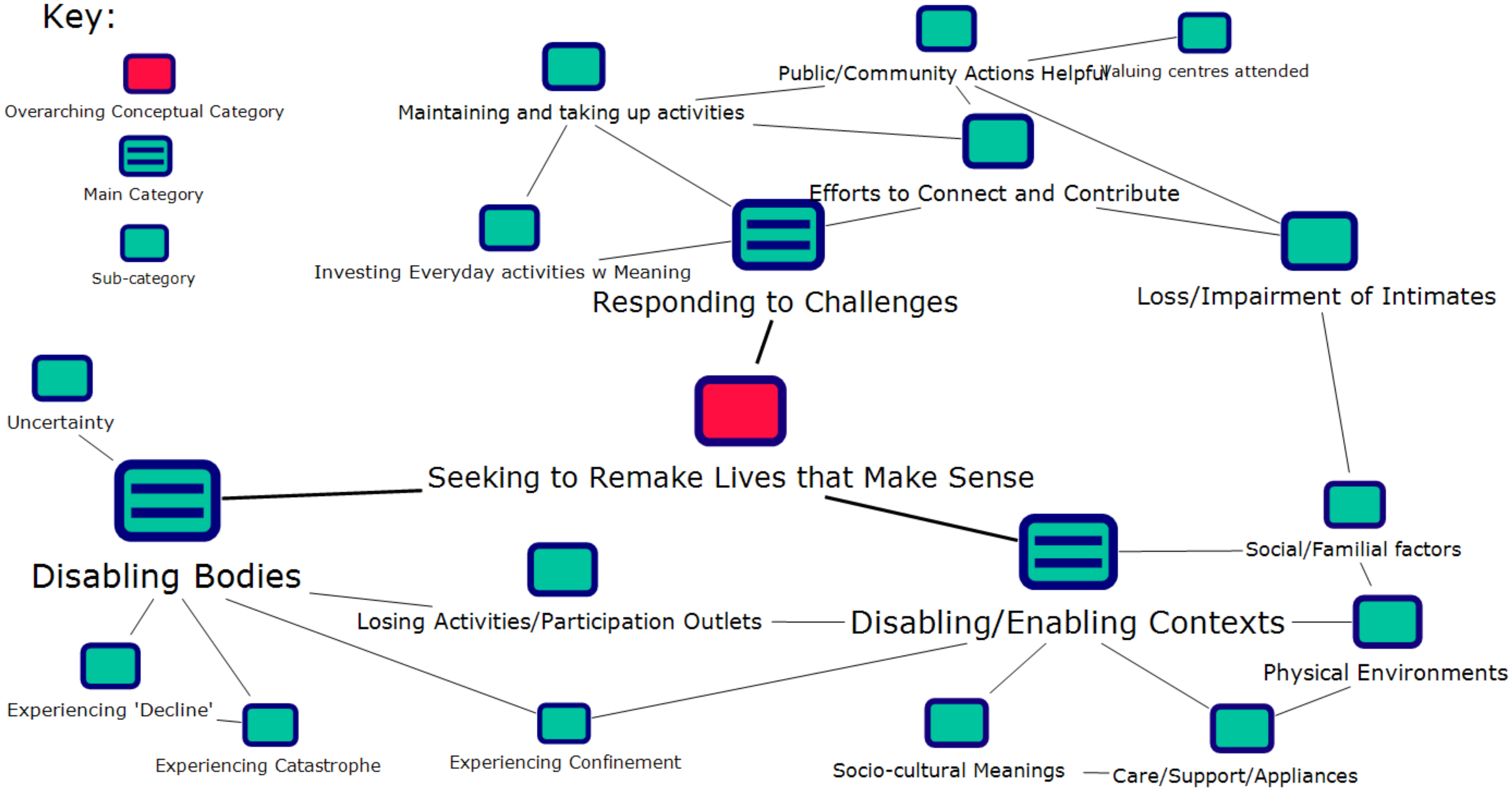
Another issue is that I interviewed only those who had the ability to verbally communicate and so the sample is biased toward those able-bodied enough to share their stories. I would also have liked to have included some lifelong deaf people to compare with those experiencing hearing impairment with ageing. However, I already explained the reasons why this proved impossible.

An obvious possible limitation is that I recruited more women in one category – AwD – than men (F=13; M=5). While overall the greater number of women in the study is justifiable, I believe, as it reflects the wider demographic context (see above), it would have been preferable to have had a better balance between men and women in the AwD sample. However, a much longer field-work timetable would have been required for this, and, like most research, a doctoral researcher is limited in terms of time and resources

Concluding Remarks

In this Chapter, I set out the study’s empirical research design, including its methodology and methods. I presented an overview of the categories identified in the study (and the linkages between them) whose data have not yet been presented. Thus, I will present the findings using the three main categories as headings in Chapters that follow (7, 8 and 9), which provide descriptive and interpretative accounts of what I identified within the data from the interviews. But first, in **Chapter 6**, I report on findings from interviews with policy-makers, service providers and representatives of advocacy organisations. This also contextualises and provides background on the public policy environment that impacts on older disabled participants, and, therefore, it is relevant also to the findings reported in all subsequent Chapters.

Figure 5. 1 Diagram of Overarching Conceptual Category: Seeking to Remake Lives that Make Sense



CHAPTER 6 – FROM BEHIND AN ‘OPAQUE GLASS WALL’: FINDINGS FROM INTERVIEWS WITH POLICY-MAKERS, SERVICE-PROVIDERS AND ADVOCATES

6.1 Introduction

This is the first Chapter in which I present findings. The findings I present here address the separation of policies on ageing and disability. A long-standing concern of critical gerontology is to reveal policy assumptions relating to older people and their (often) negative practical implications (Means 2007:45). This concern underlies this study generally and it is a concern that is immediately relevant to the interviews I carried out with policy-makers, service providers and representatives of advocacy organisations, which is the subject of this Chapter. The research questions for this investigation are:

- How does the chronological boundary of age 65 operate between services for disabled people and older people in practice?
- How do people working in these fields relate to this separate organisation of service? and
- What are the implications for disabled older people?

The review of Irish public policy included in **Chapter 4** forms a directly relevant backdrop to this part of the study. Consequently, I start this Chapter by briefly recapping some of its conclusions. I then outline again the profile of participants and I describe the categories I identified arising from the analysis for this part of the study. In the main part of this Chapter, I describe and discuss findings, and these have already been published (Leahy 2018). I use as headings the three categories I identified in the data: how disability in older age is understood, how services are conceived of for disabled people and older people, and practice issues.

I found that the medical model dominates approaches to social care for older people in Ireland. Understandings of disability in older age (or the lack of them) and the funding/administrative boundary between the two service frameworks legitimated separate models for disabled people and older people. Thus, some participants associated disability acquired in older age with decline and end of life. Consequently, they thought it appropriate that older people’s services be more medicalised and less socially-orientated than those for disabled people. Even participants who disputed the domination of medicalised approaches to social care for older people, lacked terms or concepts with which to discuss people who experience impairment in older age. This has implications for older disabled people as it contributes to keeping in place medicalised, reductionist notions about the nature of disability in older age, it influences the nature of services available to them and, doubtless, the separate policy frameworks also affect how older people view themselves.

The findings also highlight anomalies in practice to which the separate organisation of the two services gives rise, the most fundamental being how a small difference in timing of disability onset around one's 65th birthday can determine an engagement thereafter with one of two services that are conceived of and delivered differently. For those ageing with disability (AwD group), the picture that emerges is a confused one as to which sector is responsible, and, consequently, as to what their experience of public services will be from age 65 on. Thus, my findings suggest that the confused position for this group found in explicit policies, as discussed in **Chapter 4,** is reflected in inconsistent practices in service provision.

6.1.2 Recap: Policy Background

My review of policies (**Chapter 4)** suggested that explicit Irish public policy was not clear as to which service is responsible for those ageing with disability (AwD). It also suggested that:

(1) neither the older people's sector nor the disability sector now articulates comprehensively values, aims and desired outcomes for disabled older people in overarching policies/strategies (neither for DwA nor AwD),
(2) policy-making (on ageing and on disability) proceeds on parallel lines out of different models of disability, with disability policy influenced by social model and human rights approaches, and older people's policies operating out of the narrower medical model, and
(3) there was little evidence of an active interface between the two sectors, or of learning from one another, and, instead, some instances of each reproducing, respectively, ablest or ageist assumptions.

Thus, I concluded that there were conceptual issues and issues to do with how services operate in practice at the interface of the two frameworks that I could address with those working in the fields of disability and ageing.

6.2 Analysis

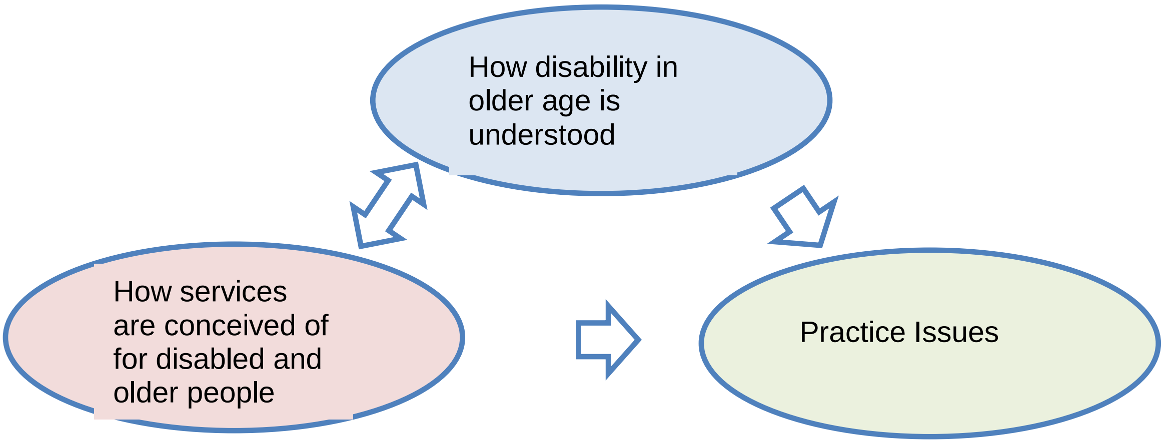
The methodology for this study has been already outlined in **Chapter 5.** For this part of the study, there were 16 participants recruited from organisations working in ageing or disability in three areas: policy-making/ advising (n=4), management/coordination of services supporting people to live in the community (n=6), and advocacy or related activities within NGOs (n=6). There was also a representative of an NGO whose remit crossed over the two sectors. See **Table 5.1** in **Chapter 5**.

For clarity, I concentrated in **Chapter 5** on reporting my analysis of interviews with older people. For this part of the study, again using an inductive, interpretive analysis, I identified the following three categories:

(1) how disability in older age is understood,
(2) how services are conceived of for disabled people and older people, and
(3) practice issues.

The first and second categories were mutually reinforcing. Category 1, ‘how disability in older age was understood,’ was the core category because it was embedded in segmented institutional arrangements and the funding boundary between the two services, and it in turn reinforced or legitimated distinct types of supports and services thought appropriate or inappropriate to the two groups (Category 2). Both then influenced the third category, practice issues – which involves factual issues relating to how services are provided at the interface between policies on ageing and disability. See **Figure 6.1.**

Figure 6. 1 Findings from Policy-makers and Others: Three Categories



6.3 Findings

I present findings here using the three categories just outlined as headings, starting with how disability in older age is understood, then considering the second, how services were conceived of for disabled people and older people, and finally, the third, practice issues.

6.3.1 How Disability in Older Age is Understood

Participants often had no concept of disability with ageing, and identified older people acquiring impairments as just ‘elderly’ or ‘older people’. Those participants who did consider that people first experiencing impairment in later life could be encompassed within the category ‘disabled’ tended to come from the non-profit disability sector and invoked a biopsychosocial model of disability. A key finding was that understandings of impairment or disability in older age (or the lack of them) were informed by, and constructed in terms of, the segmented institutional arrangements and funding boundary between the two service frameworks, and both influenced thinking about distinct types of supports and services being appropriate to the two groups (that is, older people and disabled people generally).

No Concept of Disability in Older Age?

People in both ageing and disability fields felt that there was no concept of ‘disabled older person’ except for someone who was ageing with lifelong disability. People who experienced impairments with ageing were considered not ‘disabled’ but ‘old(er)’ or ‘elderly’. For example, a manager of a medical day centre for older people considered that her client group often experienced disability, by which she meant not regaining full functioning, but were thought of as ‘older people.’

A senior person from an age-sector NGO said that when she thought of an older ‘disabled’ person it was someone who experienced lifelong disability. She described how in the past ageing and disability were synonymous - ‘maybe old equalled disabled’ – and how age-organisations resisted this conflation. A policy-maker/advisor on ageing articulated a similar view, taking issue with the fact that older age was often thought to be synonymous with disability. Another staff-member of an age sector NGO described how the focus in her organisation is on active ageing and ‘continuous engagement’, which, she acknowledged, is understood to mean being able-bodied. The concept of the ‘third age’ is used, but the ‘fourth age’ is never mentioned. Terms like ‘disabled’, ‘frail’ or ‘impaired’ are not used. She reflected during the interview that this means that her organisation is identifying with one group of older people but not another:

> It is very interesting, me reflecting on this now, you are giving me new thoughts. The whole definition of engagement implicitly means able to engage, that you are abled bodied, able to get around (staff-member, NGO-ageing 2).

But she also reflected how some of the work involves an implicit understanding that people are at risk of isolation due to disability:

> So, while the word ‘disabled’ isn't used around that table, I imagine implicit in that [is that] people are being befriended at home because they have a disability and can't get out (staff-member, NGO-ageing 2).

These findings are consistent with findings from other studies of a tendency to define older disabled people as ‘elderly’ rather than ‘disabled’ (Jönson and Larsson 2009). Those ageing with disability are considered ‘disabled’ while persons who experience disability for the first time in later life are not. Thus, the findings reflect an understanding of disability as generationally situated (Priestley 2006) with age, impairment and disability conflated in later life (Grenier, Griffin and McGrath 2016).

This represented a paradox for some participants. They contend with a generalised conflation of the concept of older age and disability, frailty or functional restrictions, and seek to distinguish most older people from this image. Yet they also do not have a language with which to talk about older people who *do* experience onset of impairments or disability, other than it being implicit in some understandings of what it is to be older and marginalised or isolated. There is a sense of concepts like ‘third age’ or ‘active ageing’ ‘obliterating’ or ‘cancelling’ the so-called fourth age (Timonen 2016:81) in rhetorical terms.

Disability in Older Age equated with Decline?

There was a tendency on the part of some of those working on disability to explain the distinction between disability services and older people’s services on the basis that what people experience in older age is not disability, but ‘decline’ linked to end of life. This was articulated by personnel in statutory organisations and was associated with the view that older people’s services needed to be more medicalised and have less focus on social or community participation. For example, ‘decline’ was used to explain the division between services for older people and disabled people:

> But the disability directorate doesn't deal with people who are gradually crumbling with old age…. the declining physical and other capacities of old age was for older person's services (Policy-maker/advisor, disability 1).

But an assumption that disabled older people are experiencing ‘decline’ and that consequently it is appropriate for services not to focus on social and community participation risks overlooking how people live with chronic illness over time rather than die from it (see Verbrugge and Jette 1994). It also overlooks the tenacity and efforts of disabled, frail and/or ill older people to continue to engage with life as evidenced in a series of studies (Grenier 2005; Murphy *et al.* 2007; Nicholson *et al.* 2013; Lloyd *et al.* 2014; Warmoth *et al*. 2016; see **Chapter 3).** For example, people aged 86-102, categorised as frail, demonstrated engagement in ‘extraordinary work’ involving creativity and capacity to overcome (or find others to overcome) physical, emotional or social vulnerabilities (Nicholson *et al*. 2013:1179).

However, other participants working on the disability side saw a more nuanced picture. One staff-member of a disability NGO identified the lack of, and inflexibility of, services to support older people to live at home as a *disability* and a *human rights* issue, specifically as a denial of rights under the UN Convention on the Rights of Persons with Disabilities, even though she was also aware that older people are not thought of as disabled.

This participant and others working in disability articulated an understanding that disability can be experienced across the entire lifespan, one capable of encompassing both the AwD group and the DwA group. Other participants too referred to the U.N. Convention on the Rights of Persons with Disabilities (United Nations General Assembly 2006) in the same way.

Funding Boundary Constructs How Disability in Older Age is Understood

Participants demonstrated that the funding boundary at age 65 (itself, of course, an arbitrary age but one reinforced by administrative systems like pensions) influences how they thought about both what it is to be disabled and older and also about the nature of supports and services. Repeatedly, how disability is understood in older age was linked to how services for this group were organised. For example, asked how disability with ageing was understood, a manager of services to older people within the Health Service Executive said, ‘if you acquire a disability as an older person, the care and support is based around literally the maintenance of immediate activity to daily living’.

Also responding to this question by reference to how the services are organised, a participant working in a disability organisation described a ‘medicalised notion’:

> …if I was to think about it in very simple terms it's the very passive person who's probably got a limited range of services, just left there you know with nobody...not being able to advocate for themselves or for others. It's very much….that medicalised notion (NGO staff-member, disability 1).

But she was aware of holding contradictory viewpoints, and she went on to convey another view:

> If you were to ask me to put my social policy hat on then it would be something that's quite different, because I think as we all are growing older we all acquire some form of disability and there are so many older people who are living well with the disability of whatever shape or form it is (staff-member, NGO-disability 1).

Some of those working on the disability side thought that a distinction was appropriate between the aims of policy for disabled people under and over 65, and, in discussing this, demonstrated how the funding boundary affected their understanding. Thus, one manager of services for disabled people approved of the disability policy *New Directions,* which, as he explained it, aims to support people to access ‘employment and education and community’ and as ‘a personal support to have a life’. He felt that this approach was not appropriate to disabled people over 65. He added that he could possibly envisage this approach for long-term disabled people already within disability services, but not for other people aged over 65.

Later in the interview, this participant identified contradictions in his thinking, saying that people had the right after age 65 to have ‘a full life’. He added, ‘I’m blocked in my 65s...over 65s,’ and went on to outline how the separate funding streams dictate and limit thinking on the issue:

> I think most people over 65, a lot of them will have a disability of some sort. … the different definitions of disability would capture a lot of people over 65…but they are not seen as disabled people. They are seen as elderly….I think it’s goes back to the traditional set up of the Health Act, and the divide of stuff for people into under 65s and over 65. It seems to be embedded in the system, you know. It seems very hard to shake your way out of it. It’s kind of like at the minute over 65s - not ours..…. (Service Provider 1, disability).

Thus, he identified contradictions in his thinking embedded within the organisational and funding structure within which he works, and which affects how disability is understood and how services are conceived of for disabled and older groups. He explained this in terms of the funding boundary and funding constraints, which made it impossible for him to envisage taking on an additional client group (that is, people first experiencing disability from age 65).

This participant’s thinking reflects institutional structures that mean that ‘the status of the disability is bureaucratically ‘frozen’’ (Rickli 2016:126-7). Thus, it illustrates how the administrative/funding boundary constructs the lifecourse and the meaning attached to the experience of impairment at different life-stages. In the thinking of this participant, it creates a distinction between people who belong to the same chronological cohort but with different timings of disability onset - with those whose disability onset predated their 65th birthdays being more likely to continue to be considered ‘disabled.’ For that reason, he considers it more appropriate for people already within his service by age 65 to continue to be included within more socially-orientated disability services thereafter.

6.3.2 Conceptualisation of Services for Older People and Disabled People

The second category identified in the data concerns how services were conceived of or delivered for older people and disabled people and whether participants perceived the differences to be appropriate. In general, participants highlighted how a more medicalised and less self-directed approach was a feature of older people's services. Those working within older people's services critiqued this as did several of those working in disability. However, some working on disability – including those working at a senior level - outlined how they perceived certain differences as appropriate, and this related to how they understood disability and ageing.

Older People's Services – Narrow and Medicalised rather than Holistic

Most participants characterised older people's services as over-medicalised and narrowly focused on basic physical functioning, ignoring emotional and social sides of older people's lives. A manager of services for older people within the Health Service Executive described the emphasis on 'maintenance'. He considered that, by contrast, services for younger disabled people would include a focus on participation as a right:

> ...if you acquire a disability as an older person, the care and support is based around literally the maintenance of immediate activity of daily living…..this would focus on your ability to get up washed and dressed, fed, and that would be about the sum of it. But if you have got a disability and you are younger then there might be more thinking about the fact that you continue to have a human right to participate in society, to be able to get to the shops, to be able to go to events.…but once you turn 65 that doesn't exist (Service Provider, ageing 1).

He instanced conflict with clinical staff about what home support should include. He felt that walking someone's dog or accompanying them to a religious service was person-centred care. But clinical staff considered this as too broad, which he attributed to prioritisation of scarce resources through the lens of a narrow medical model. This echoes criticism from gerontologists of the narrow focus on functioning in public policies and practices (see Lloyd 2012:113).

As already outlined, a small number of those on the disability side thought that differences were appropriate in the approach to services for the two groups – specifically, that more medicalisation and less focus on community participation was appropriate within older people's services. This was associated with an understanding of disability in older age as tantamount to decline and end of life, as already discussed, and with an assumption that older people already have 'natural' family and community supports. It was also associated with funding issues and service pressures and a consequent wish to maintain a focus on the existing client group (that is, disabled people).

Disability Services – Independence and Self Direction?

In contrast to older people's services, disability services were thought by participants to aim to provide a more comprehensive range of services, including rehabilitative approaches, and to operate in a more flexible and self-directed way. This was considered an appropriate aim. However, it was also described as limited in practice. Instead, for most people, an administrative system was described as still operating:

> The HSE decides how many hours [of support to live at home]. Only a very tiny number of people have a personal budget where they go off and they do their own [thing]...(Policy-maker/advisor, disability 1)

Participants also instanced younger disabled people experiencing insufficient supports to live at home and a lack of rehabilitative therapies and they felt that provision overall was not as comprehensive as it might be.

Participants perceived that a medicalised approach operated at times within disability services – sometimes considering it inappropriate and sometimes as an appropriate response to significant medical needs. The exigencies of that care were perceived as contrasting with the lower levels of support that might be needed for an older person who needs supports to live at home, such as help with some tasks (like washing or dressing), but otherwise to be able to perform other activities of daily living independently. This perception is perhaps ironic given the medicalised emphasis in older people's services and, indeed, given the views of some of these same participants that this was appropriate for older people

6.3.3 Practice Issues - How service-boundaries operate in practice

The third category deals with how services operate in practice, addressing which service is responsible for what groups of people, gaps in services, and whether participants perceived that greater integration of the two (that is, disability services generally and older people's services) was desirable. My analysis suggests that in practice, as well as in explicit policy articulations (which I reviewed in **Chapter 4**), the position is somewhat inconsistent as to what service is responsible for those ageing with disability (AwD) from age 65 on. Participants identified gaps in services common to both services (that is, services for disabled people generally and for older people). Some described the strict division between ageing and disability approaches as illogical and cumbersome, not delivering person-centred care/support, and creating anomalies. They were also apprehensive about possible change, suggesting that reconfiguration might be attempted as a cost-saving measure that would result in poorer services for one or both groups.

Clarification of Service Responsibility: Ageing with Disability and Disability with Ageing

A key factual issue on which I sought clarification was which service is responsible for the AwD group once they reach age 65. This followed my review of explicit policies discussed in **Chapter 4,** in which some written policies suggest that older people's services are responsible (see Expert Reference Group on Disability Policy 2010; Working Group Report (HSE) 2012). I found that in practice, as well as in explicit policy articulations, the position is somewhat inconsistent.

On the one hand, a senior policy-maker within the statutory disability sector stated that disability services remain responsible for the AwD group, framing this as something clarified recently:

> They have said to us in the last couple of months that we continue on our services for people who are older who are part of our services, that that continues beyond the 65 (Policy maker/advisor, disability 1).

In practice also, several service providers in both ageing and disability confirmed that this is how things operate. For example, a senior manager of services for disabled people confirmed that people remain within his service after age 65, explaining this because of the desirability of continuity and because day care centres run by older people's services are not always wheelchair accessible.

Managers of specific services for disabled people also confirmed that this is how they operate. One day-centre had clients in their 70s and 80s who had experienced disability-onset prior to age 65. Its manager felt that they fitted well with the service and were as active as younger members:

> [older members have] more interest in the QQI [accredited] learning than younger people……and a great interest in getting out on trips and going to all sorts of different places (Service Provider, disability 3).

She perceived that the alternative – day care services provided by older people's services - tended to be 'slower', more medicalised, more limited in terms of hours/days available and sometimes lacking transport altogether.

However, on the other hand, I also encountered examples that ran counter to this approach - where disabled people were transferred on reaching age 65 to older people's 'homecare' services. Thus, a senior manager in a national disability organisation, providing support in the community to disabled people, had experience of the Heath Service Executive transferring clients at age 65 to a home care provider within older people's services. She perceived this as happening only in some parts of the country and perhaps on a discretionary basis. In her view, this represented a shift from a case-managed rehabilitation-based service to a purely task-based 'care' model that was not comprehensive or responsive to clients' needs. She believed that as a result of the more 'task' based model, clients could end up being admitted to residential care sooner than necessary. She described the difference as follows:

> … the big difference is this………the rehab model. It helps to maintain what you have and pushes you to get a little more, even though you may have a progressive illness. You don't get that with a homecare person coming in. It's task orientated. It's washing, bathing. This [rehab model] is different. It looks at the whole environment… It's the teaching of compensatory strategies. It's the teaching of managing behaviour (staff member NGO Disability 4).

Thus, for older people who experienced disability onset prior to age 65, these findings suggest that the position in practice is not consistent once they reach age 65. For the DwA group, experiencing disability onset after age 65, the position seems consistent with the thrust of explicit policy - that they will be referred to older people's services where, of course, the language of 'disability' tends not to be used and a different model applies. Thus, people receive services that are conceived of and configured differently depending on whether they are under 65 or over when they first experience disability.

Gaps in Services for Disabled People and Older People

Participants identified several gaps common to disability services and older people's services. Chief amongst them was underdevelopment of community services resulting in a lack of support for people to live at home. This support was perceived to have been severely reduced by funding cuts in recent years. A few participants highlighted that while disability services might aim to be more broadly-based than (task-based) older people's services, getting access to services for disabled people could be difficult, especially in some parts of the country.

As well as inadequate levels of services provided, participants highlighted inflexibility in the way services were provided, particularly within older people's services. Examples involved older people being offered assistance with getting to bed unacceptably early (at 6pm in one case), or services being inflexible and not adjusted to needs (say, not capable of being provided at different times on different days) while those who could afford to pay for private care could have supports delivered in more flexible ways.

For older people, another perceived gap was lack of step-down facilities or intensive home supports that would help to restore functioning, and a consequent requirement to admit people to nursing homes where, by and large, rehabilitation stops. Consistent with the identification of a lack of home supports, those engaged in service delivery referred to the bias of services toward residential care, often perceiving that NHSS (or Fair Deal scheme), being statutory, reinforces this bias. This bias was referred to especially in the case of older people, but also for younger disabled people with higher care needs or in geographical locations where other services are insufficiently or not at all available[52]. Indeed, this is consistent with the findings of existing studies (Donnelly *et al*. 2016) and advocacy positions (Disability Federation of Ireland 2012).

Other gaps identified as affecting both disabled and older groups included lack of intermediate housing options, and lack of therapies (such as physiotherapy and occupational therapy) to support/restore functioning. One service provider on the ageing side characterised physiotherapy and occupational therapies as vital following a stroke, but not always available on the public system. By contrast, some people who have the means and the information can obtain therapies privately irrespective of their judged 'potential'.

Participants highlighted some specific groups that are negatively affected by the division between disability and older people's services. Concerns raised related to dementia, particularly lack of appropriate routes and services for people with a diagnosis prior to age 65 (as dementia services are located within older people's services), something also highlighted previously (see Conroy and Mangan 2006; Murphy *et al*. 2007).

Thoughts about greater Services integration

Not all participants had a view on whether a greater degree of integration was desirable. But several anticipated that increased population size and demographic ageing would bring changes in service configuration. Several participants described the strict division between ageing and disability approaches as illogical and cumbersome, not delivering person-centred care/support, and creating anomalies for some groups. Some considered the current situation arbitrary and wrong. One said:

> ….there is something inherently and systemically wrong with the way we are designing our services…..I appreciate you need some sort of structures but the chronological age is not a good way (Staff-member, NGO-disability 1).

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[52] News reports from August 2017 suggest that 1,222 disabled people under age 65 live in nursing homes and that the Health Service Executive considers this to be a 'clinically appropriate' response for some but that home support would be more suitable for others (RTE 2017)

One described an ‘opaque glass wall’ operating between the two sectors – amongst statutory organisations and amongst NGOs - which resulted in neither learning much from the other and sometimes trying to reinvent the wheel (Policy maker/advisor, disability 2).

But these participants were also apprehensive that attempts to save costs might be presented as attempts to integrate the two services and result in a diminution of services for one or both groups. As a prerequisite for change, one person emphasised the need for conceptual change:

> My concern with the way in which much, not all, much service change in Ireland has been undertaken in the past is that it would actually wind up as a cost-saving exercise and therefore be a levelling out to the lowest common denominator ……And it seems to me that any attempt to make service change without first really interrogating attitudinal constructs is doomed to repeat the failures of the past or the exclusions of the past (Policy-maker/advisor, disability 2).

These are legitimate concerns. It is complex to sustain bridges between the two fields (Putnam 2007). It is obvious why advocacy for disabled people attempts to link rights for disabled people to those aimed at children and adults below retirement age – to be considered entitled to the full participation and activity afforded to adults (Jönson and Larsson 2009:70). Walker and Walker (1998:127) illustrated how ageist assumptions and stereotypes built into ‘normal’ patterns of care for older people operated destructively when applied to the AwD group; looking at the situation of community-dwelling people ageing with learning difficulties, they describe how as soon as an individual is transferred from one service category to another due to chronological ageing, ‘the orientation of services shifts from supporting independence to reproducing dependence’.

6.4 Discussion

In this Chapter, I reported findings from my interviews with people working in Irish social care in policy-making, service provision and activism in the two fields of ageing and disability. This part of the study (whose key findings have already been published – Leahy 2018) fits within a critical gerontology tradition that critiques policy assumptions relating to older people and seeks to unmask their practical implications (see Townsend

1981a; Means 2007:45) and with a social constructionist approach to the lifecourse that investigates *how* social realities are constructed (Holstein and Gubrium 2000:2).

I found that how disability in older age was understood, and how the administrative/funding boundary between the two services was constructed were mutually reinforcing and served to legitimate how services are separately conceived of for disabled people, on the one hand, and older people, on the other. This echoes Putnam’s (2011:338) suggestion, in a similar context, that it was an open question as to whether the ‘policy regulations drive professional perceptions or vice versa’. The findings also highlight some anomalies in practice in the way that services are organised for disabled older people.

I found that participants often had no concept of disability with ageing, and identified older people experiencing impairment with terms like ‘just elderly’. A ‘disabled older person’ was someone who was ageing having lived with lifelong disability. This represented a paradox for some of those working on ageing who rejected a conflation of the concept of older age and disability (or frailty, ill-health or functional restrictions), as they did not have a language with which to talk about older people who *do* experience onset of impairments or disability. In addition, adherence to positive ageing concepts meant that some participants from age-organisations identified only with able-bodied older people. This suggests that older people experiencing long-standing disability may be at risk of exclusion or marginalisation in mainstream senior outlets (as found by Raymond and Grenier 2013; Raymond, Grenier and Hanley 2014: 57). However, I found that this exclusion might well affect the DwA group as well as the AwD group.

Some participants working in disability perceived that a policy-model focusing on community involvement was appropriate for disabled people generally, not older people, influenced by thinking that disability in older age is about decline and end of life and that older people already have social support from families. Grappling with the institutionalised boundary could lead participants to positions that they sometimes also acknowledged as paradoxical. It could, for example, lead to perceptions that distinctions might be appropriate between older people in the same age-group with different timings of disability onset, specifically that it was appropriate that those already within disability services at age 65 should be included within the community and socially-orientated aspects of disability services thereafter, but not people of the same age first experiencing disability after age 65. This was influenced by funding constraints and service pressures.

Significantly from the perspective of this study, this illustrates how the administrative/funding boundary constructs the lifecourse and the meaning attached to the experience of impairment at different life-stages in participants' perceptions. This has implications for older people because it contributes to keeping in place reductionist notions about the nature of disability in older age and it affects the nature of services available to them. Of course, as I argued in the Introduction to this study, the separate models and organisation of public policies on ageing and disability have further implications, as public policies also shape personal identities of older people and define 'the parameters of legitimate ageing' (Estes, Biggs and Phillipson 2003:4,67). Critical gerontologists have long argued that social structures affect not just how older people are viewed but how they view themselves (Estes, Biggs and Philipson 2003; Holstein and Minkler 2007:18). Likewise, constructionist interpretations of the lifecourse suggest that policies frame expectations of later life and provide typical constructs from which events and interactions are perceived and experienced (Grenier 2012:65). In short, as currently organised, social policies in Ireland suggest that one is either 'disabled' or 'older' not both, something that doubtless influences how older people view themselves – something I come back to in later Chapters.

Some participants considered the strict administrative and funding boundary between the two sectors as illogical, inflexible, and not delivering person-centred care/support. One characterised the operation of the two services as divided by an 'opaque glass wall', preventing either learning from the other. Participants sometimes anticipated that demographic ageing would lead to changes in the current configuration but were apprehensive that attempts to integrate the two services would also aim to save money and diminish current levels of support for one or both groups. This is a reasonable concern.

Criticism from participants working on ageing of over-medicalisation of social care for older people and lack of attention to social and emotional needs, echoes criticism from gerontologists that social care practices for older people based on the medical model are often overtly or covertly ageist (Heywood *et al.* 2002; Oldman 2002). It also echoes criticisms that are associated with the emergence of disability activism and disability studies, as over-medicalisation is precisely the critique in relation to disability generally mounted from the 1960s that led to the development of social models of disability. For example, Brisenden ([1986]1998:20) described the medical model of disability as:

> …. rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual.

The findings I report in this Chapter confirm my contention in the introduction to this study that the medical model has ‘scarcely been challenged’ in policies on ageing (Oldman 2002:795).

Participants who showed an understanding of the category ‘disability’ that could encompass both the AwD and DwA groups, tended to employ the definition of disability from the U.N. Convention on the Rights of Persons with Disabilities. I quoted from this in **Chapter 2**, and the point I emphasise here is that the Convention is not widely applied to older people. According to the European Network of National Human Rights Institutions (2016), limited views of what constitutes ‘disability’ are thought to play a role in this. These findings confirm again the argument I made (in **Chapters 2** and **4**) that shared understandings of what disability is are necessary to facilitate linkages between policy and services, research and activism on ageing and disability, and that biopsychosocial understandings of disability may be capable of providing such a framework.

Turning to what the practical implications for older people are of the boundary between the two services, I found several anomalies. For the AwD group, the picture is a confusing one, both as to what happens in practice, and (from my review reported in **Chapter 4**) as to explicit policy. Upon reaching age 65, there could be continuity for the AwD group, or there could be disruption. The former happened when centres run by disability organisations continued to include clients who had experienced disability prior to age 65 – resulting in the anomaly that disability centres could have clients in late older age, but *only* those who first experienced disability prior to age 65 (even if only just before their 65th birthdays). On the other hand, disruption and diminution of services could be experienced if those experiencing AwD were transferred at age 65 to older people's homecare services, perceived as more task-based with less emphasis on rehabilitation. This was a practice that appeared to operate in some geographical areas and/or on a discretionary basis.

On the other hand, if the DwA group experience disability for the first time from age 65 on, they are likely only to encounter older people's services, and thus a small difference in timing of disability onset around one's 65th birthday results in experiencing a service model that is conceived of and organised differently. Specifically, the DwA group (if they experience disability after age 65) cannot benefit from specialist disability services that can include Personal Assistants, support workers and various rehabilitative services. This is consistent with studies from other countries suggesting that older people are provided with services of lower quality than those given to their younger peers (Jönson and Larsson 2009), or experience a narrow range of services (lacking physiotherapy, occupational therapy and social work) (Bowling, Farquhar and Grundy 2008). That being said, I also acknowledge that Irish social-care services are not as comprehensive for many disabled people as participants thought necessary.

Issues and anomalies evident from the findings illustrate the need to critically engage with ageist assumptions that underlie the provision of aged-care. Unconscious ableism as well as ageism may be operating. Specifically, elements of ableism can be seen in the distancing by those working on ageing from concepts like disability. Elements of ageism can be seen in the equating of older age and end of life (and consequent downplaying of social needs) by some working on disability. This confirms how 'mutual discrimination is to some extent present in the very struggle against ageist and ablest norms' (Jönson and Larsson 2009:75).

Finally, as well as illuminating some of the practice anomalies and difficulties to which current segmented approaches give rise, this study adds to an emerging body of knowledge about what some of the barriers might be to bridging the two fields of ageing and of disability (see Putnam 2011;2014; Keefe 2014; Bigby 2008 and **Chapter 4**). It does so by highlighting the issue of unconscious ableism and ageism, professional investment in age-segmented approaches, and different logics/philosophies that underpin the two sectors. These issues, I suggest, need to be articulated and addressed before attempts at integration are attempted.

6.5 Conclusions and Implications

I found that the medical model dominates approaches to social care for older people in Ireland. How disability in older age was understood and the funding/administrative boundary between the two service frameworks were mutually reinforcing and both served to legitimate how services are differently conceived of for disabled people and older people. Thus, participants often had no concept of a 'disabled older person' (other than someone ageing with lifelong disability). And some participants explained this by linking disability experienced first in older age with decline and end of life, and consequently thought it appropriate that older people's services be more medicalised and less socially-orientated than those for disabled people.

This means that the separate frameworks for policy on ageing and disability contribute to keeping in place reductionist, medicalised notions about the nature of disability in older age. Neither sector learns much from the other. This affects disabled older people by influencing how services for them are conceived of and what is thought appropriate for the two groups (that is, disabled people generally and older people), and it suggests that one is either 'disabled' or 'older' not both, something that doubtless influences how older people view themselves.

I argued that elements of ageism and ableism contribute to the maintenance of barriers to closer working between the two sectors as does the lack of a concept of disability with ageing, as participants often lacked a language with which to discuss older people who experience onset of impairments or disability. Thus, these findings reinforce what I have argued already, that at a fundamental level there is a need for a shared understanding between the disability and age sectors of what constitutes disability in older age.

I found some anomalies in practice to which the current segmented approach gives rise. Most fundamentally, a small difference in timing of disability onset around one's 65th birthday will determine an engagement with services that are conceived of and delivered differently. I found inconsistent approaches to the AwD group once they reach the service boundary defined by age 65, but that some experience diminution in services if transferred to older people's homecare services. This confirms the need to challenge ageist assumptions that underlie the provision of aged-care.

I suggest that implications for Irish public policies include the need for more interchange and learning between the disability and age sectors in research, policy-making, practice and advocacy, involving interrogation of their respective definitions, informing philosophies and concepts and resulting practices. Furthermore, policies for ageing populations need a specific focus on the particular situation and needs of the AwD group, not least because without a specific policy focus, their position from age 65 may be worked out in ways that are not transparent or consistent.

Concluding Remarks

In this Chapter I discussed findings from interviews with policy-makers, service-providers and representatives of advocacy organisations in the fields of ageing and disability in which I revealed assumptions that underlie how services are (separately) organised on disability and ageing and some practical implications for older people.

In the next three Chapters I present findings from my interviews with older disabled people of experiences and meanings made of disablement processes.

CHAPTER 7 ‘MY BODY JUST IS JUST TELLING ME, ‘YOU CAN'T DO IT’’: BODIES PERCEIVED (OR NOT PERCEIVED) AS DISABLING

7.1 Introduction

This is the first Chapter presenting findings from the main part of this study – with older disabled people, those experiencing disability with ageing (DwA) and ageing with disability (AwD). It is the first of two Chapters addressing the research question of ‘how do older people experience disablement processes and what meanings do they make of those experiences?’ In it I discuss the first main category I identified – disabling bodies.

Joan (aged 86,DwA) said that the things that could most improve her life were a new body and a local bus (she lives in the country and drives less than formerly). Implicit in this is an understanding of ‘disability’ that is experienced in the body and in the way that the body interacts with broader contexts. In this Chapter**,** I focus on the first of these – disability perceived in the body, considering the physical reality of the body as it impinges on identity, because how we understand and experience bodies links with how we think about identity (Battersby 1993:31; Charmaz 1995; Hockey and James 2003). Joan’s reference to a local bus implies that contextual factors other than bodies were also relevant. Some participants were highly conscious of disablement experienced in relation to broader society – such as inaccessible physical environments or discrediting reactions of others. I return to this aspect in **Chapter 8.** Part of the discussion there – that related to socio-cultural meanings made of disability – is also relevant to bodily issues, that is, to the appearance of the body.

I start this Chapter by briefly discussing, by way of background, relevant theoretical concepts, clarifying what I mean by identity, and my approach to the body, and finally concepts from medical sociology, which I use to discuss the findings.

In the main part of this Chapter I show how participants experienced disablement (onset or worsening) in their bodies, meaning that bodies limited their activities and sometimes caused pain and fatigue. That bodies could be perceived as disabling or limiting (or more disabling or limiting for the AwD group) is not surprising. But I found that participants experienced consequent suffering and loss, they perceived uncertainty about daily life and the future and they were forced to abandon social activities and roles as direct consequences.

I show that all of this can involve a fundamental re-thinking of biography and self-concept, even when disablement occurs gradually and at a stage in life when impairment is considered ‘normal’ or ‘on-time’. This is significant, because the normative connection between impairment and older age leads to some assumptions that onset of impairment in later life might be an anticipated, not disruptive, occurrence, and that the AwD experience might be one of continuity with age not change. Also significant is that participants did not define themselves by their bodies and often concentrated on what they could still do.

7.1.1 Theoretical Context: Identity

Both Jenkins (2008) and Hockey and James (2003) draw on the work of symbolic interactionists, especially Mead, to understand selfhood as an ongoing and simultaneous synthesis of (internal) self-definition and the (external) definitions of oneself offered by others[53]. Jenkins (2008:17,40) characterises identity as an internal-external dialectic of identification, a process whereby all identities – individual and collective – are constructed and involve meaning:

> Identifying ourselves, or others, is a matter of meaning, and meaning always involves interaction (Jenkins 2008:17).

Thus, individual identity can only make sense in relation to social identity, taking account of sameness and difference, and identification is a process – something that one does (Jenkins 2008). Similarly, taking a social constructionist perspective to the lifecourse, Holstein and Gubrium (2000:34) take ‘identity’ to be an aspect ‘of reality-constructing discourses’.

Social identities come into being through their embodiment by individuals (Jenkins 2008). Hockey and James (2003:134) suggest that we come to

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[53] While Jenkins considers that Mead’s account of selfhood offers a basis for a ‘general sociological theory of identification’, he also refers to limitations of the symbolic interactionist approach to society – as essentially consensual with power and domination under-recognised (2008:65).

know that we are ageing through our embodiment. And social identity is formed through a triangular relationship between the body, the self and society (Hockey and James 2003:214).

Similarly, considering age and identity, Hendricks (2010) argues that self-concept inevitably takes account of perceived feedback anchored in society's attitudes communicated via normative expectations, social resources and collective ideologies concerning ageing. And Holstein and Gubrium (2000:17) suggest that people glean the meaning of the lifecourse and life change through others' definitions.

Debates about identity in older age often focus on whether individual experience is determined by social/economic factors (associated with political economy perspectives) or is actively chosen (associated with post-modern perspectives) (Estes, Biggs and Phillipson 2003; Tanner 2010). Socio-cultural framings of ageing (a decline model, formerly uncritically accepted, and 'positive' 'active', 'successful' or 'productive' approaches) have become guiding narratives affecting personal identities (Estes, Biggs and Phillipson 2003:33,67).

In this study I take a position that attempts to strike a balance between opposing positions – recognising that individuals play a part in constructing their own identities, but also that social and cultural factors influence those processes (see Hockey and James 2003; Tanner 2010). Thus, meaning is both generated by the individual and structured by context (Gubrium and Sankar 1994).

7.1.2 Theoretical Context: Bodies

I return here briefly to the discussion of bodies in **Chapter 3** to clarify the position I am taking. There I showed how scholars from both social gerontology and disability studies suggest that social constructionist approaches limit examination of the body's contribution to the lived experience of both ageing and disability (Teems 2016).

Within disability studies, feminist scholars, in particular, critiqued the omission of the body from the social model of disability (see Crow 1996;

Wendell 1996, Corker and French 1999). Fantasies about the infinite flexibility of biology ‘are likely to grate’ with people experiencing the body’s limitations (Shilling 2012:xi). On the basis of experiencing two ‘painful and disabling’ conditions, Shakespeare (2014a:66) rejects disability theorising that suggests that impairment is *only* a matter of discourse. Instead, as Bury (1997:190) suggests, suffering/pain, disease, illness and death are not just historically/culturally contingent discourses.

For their part, critical gerontologists often resist the dominance of the bodily in biomedical accounts, but the body is central to understanding ageing (Twigg 2004). Recent literature on ageing focuses on the appearance of older age (see Gullette 2004; 2010) but does not engage fully with the ageing body (Higgs and Rees Jones 2009:35). Cruikshank (2008:151) illustrates how both physical experiences *and* cultural interpretations are relevant:

> If I become too stiff to walk and too bent to sit at a computer, I probably won't describe myself as “aged by culture.” Social construction carries us just so far. On the other hand, if I do last until infirm, the ways I interpret my infirmities and the ways others regard me will inevitably be determined by culture.

The approach I take is in line with feminist and other critiques of the social model from within disability studies and also with gerontological critiques of social constructionism. It recognises, as do Hockey and James (2003:214), that embodiment necessarily brings with it the social experience of ageing while not giving biology a determinging role. It is also consistent with Holstein and Minkler’s (2007:16-18) suggestion that critical gerontology must contest a tendency not to engage with the real bodies of older people, permitting the unproblematic support of positive cultural images/ representations. However, a challenge for this study and for cultural gerontology is between recognising bodily ageing while not normalising decline narratives (Tulle 2015).

7.1.3 Theoretical Context: Medical Sociology; Biographical Disruption

In the spirit of grounded theory, I tried not to impose preconceived theories or ideas on my analysis. But as I noticed that identity questions were part of how participants described their experiences, I turned to literature within medical sociology (introduced in **Chapter 3)**. Most embodiment research with older people focuses on illness experiences (Hurd-Clarke and Korotchenko 2011). As I suggested already, the concept of biographical disruption is useful in interpreting the meanings that older people make of impairment onset/worsening, because it represents an alternative to approaches that exclude accounts of the body (both from post-modernism and social constructionism). The chronic illness focus within this literature is relevant because chronic illness is the largest single cause of disability in older age (Bury 1997; Watson and Nolan 2011; Verbrugge and Jette 1994)[54].

This perspective links bodily issues to sense of self and identity, suggesting that people attempt to maintain a sense of continuity when faced with bodily change (Kelly and Field 1996; Bury 1997:192). Suggesting that the concept of identity implicitly takes into account the ways people wish to define themselves (citing Burke 1980), Charmaz (1995) found that people dealing with chronic illness implicitly form identity goals (or preferred identities hoped for) – they are motivated to realise future identities and are sometimes forced to acknowledge present ones.

In this literature, Bury (1982:169-70;1997:124) is influential, especially the concept of biographical disruption caused by chronic illness onset, which interrupts previous lifecourse assumptions and narratives in the context of healthy adults in modern cultures premised on expectation of long life and health. Key features of this concept are: (1) disruption of taken-for-granted assumptions and behaviours, (2) fundamental re-thinking of biography and self-concept, and (3) mobilisation of resources to respond. Bury (1982:169) points to how this involves changes in relationships, ‘disrupting normal rules of reciprocity and mutual support,’ and that the growing dependency involved in chronic illness is a major issue.

Bury’s (1991:461) concept of coping refers to processes of learning to tolerate illness, involving ‘maintaining a sense of value and meaning in life,

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[54] The very definition of chronic illness involves impairment: ‘Chronic diseases are long-term diseases, lasting more than six months, are non-communicable, involve some functional impairment or disability and are usually incurable’ (Department of Health and Children 2008:24).

in spite of symptoms and their effects'. Examples of coping include normalisation and bracketing off the impact of illness so that the effects on identity are minimised. This can involve maintaining as many pre-illness activities as possible and/or disguising or minimising symptoms. Bury apprehended this experience as occurring once, whereas Charmaz (1983,1995:660), who uses a similar concept called 'loss of self', emphasises how the experience of chronic illness often requires frequent adaptation, saying 'at each point when they suffer and define loss, identity questions and identity changes can emerge or reoccur'. Bury (1988) describes two types of meaning related to onset of chronic illness: *meanings as significance* related to deeper significance for identity (interpretations ascribed, including ways it may interfere with identity management within particular cultures), and *meanings as consequence* (practical and social consequences in everyday life). He acknowledged also that the two levels operate simultaneously.

From a lifecourse perspective, Williams (2000) suggested that age, timing and context might be important factors in the experience – specifically, that being older could make chronic illness biographically *anticipated* rather than disruptive and he highlighted a need to broaden the biographical focus out from middle-age. He also suggested that those experiencing a 'hard life' might not necessarily experience chronic illness as biographical disruption (rather a *normal crisis*). Contrarywise, others argued that the experience of disruption and uncertainty are magnified in older age (Becker and Kaufman 1995; Holstein and Cole 1996). Overall, however, as referenced in **Chapter 3**, the relationship between age and chronic illness in this literature remains under-theorised (Higgs and Rees-Jones 2009).

Empirical studies with older people continue to engage with the concept first articulated by Bury in 1982. Some suggest that chronic illness 'cease[s] to be 'out of place' or 'special' in older age (Pound, Gompertz and Ebrahim 1998). Instead, onset of impairment might be experienced as a reinforcement of the biographical identity of older people (Carricaburu and Pierret 1995; see Priestley 2006). Pound and colleagues (1998) explored experiences of stroke amongst predominantly older, working class people in the East End of London, who had also experienced the 2nd World War, highlighting ways in which accumulated life experiences, especially of hardship, mediated their interpretations. Other studies found mixed experiences. One study with Army veterans (average age 67) who experienced stroke found that some experienced the event as disruptive, others not (Hinojosa *et al*. 2008) and amongst the possible reasons for the latter was the construction of a strong masculine self and previous experiences of extreme challenge of combat. Another study found that some participants dealing with cancer experienced biographical disruption, while others did not, and suggests that the latter might arise from particular contexts, especially previous experiences of serious illness (Hubbard, Kidd and Kearney 2010)[55].

Other empirical studies show that disruption can apply in older age. So, while Sanders and colleagues (2002) found that older participants perceived arthritis to be an inevitable part of ageing and a predictable result of their biographies, viewing symptoms as ‘normal’ was ‘only half the story’, the other half was disruption. Similarly, in a study with people who had had strokes, Meijering *et al.* (2016) suggest that biographical disruption *can* be experienced at older ages as well as younger.

The perspective of the AwD group is largely missing from the medical sociology literature. Williams (2000:49-59) theorised that the experience of chronic illness onset might be different for someone with a lifelong disability – that the experience might be one of continuity not disruption involving *biographical reinforcement* and a sense that biographically speaking nothing had *shifted*. But Larsson and Jeppsson-Grassman’s empirical study (2012) with people ageing with disability and early-onset of chronic illness[56] suggests that the concept of disruption *was* relevant. They suggest that the reach of the concept of biographical disruption is wider than the Buryan tradition implies (a single event experienced by people previously healthy), and instead show that biographical disruptions may occur repeatedly over

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[55] A study with people whose ages ranged from 31-85 and who had been diagnosed with cancer during the previous year.

[56] This article reports on two studies, one on interviews with 14 visually impaired people over 30 years, who at the time of the last interview (2011) would have been aged between 60 and 75; the other a retrospective study with 20 people with different impairment types (including MS, cerebral palsy and spinal injury), aged 56-72.

the life span in chronically ill and disabled people, and that changes do not have to be wholly unexpected to be experienced as disruptive.

7.2 Disabling Bodies

I turn now to present my findings in relation to one of three main categories I identified through an inductive analysis – disabling bodies. Most participants felt that their bodies disabled them. They perceived that bodies limited what they could do, and this was the key way in which they experienced disability. Additionally, some experienced bodies that caused pain, fatigue and/or balance issues. They perceived consequences as ongoing uncertainty about day-to-day living and the future, and in having to let go of activities and opportunities to participate – and these consequences could cause loss and suffering. However, they often focused on what they could still do and sometimes played down the emotional and other consequences in their lives. They did not wish to be defined by their bodies or by what they could not do.

In straightforward terms, participants described not being able (or being partially able) to do things such as lift, walk, see, hear, or having an ongoing tendency to fall or to feel pain. Sometimes people talked about being ‘impaired’, ‘incapacitated’ or ‘limited’ in what they could do, or ‘restricted’ in the sense of no longer being able to do something or in having ‘restricted movement’ (Tony, aged 83,AwD) or ‘restricted to the armchair at home’ (Rory, aged 68,DwA). The key direct impacts of impairment (or worsening impairment) as they perceived it was activity limitations (and loss of associated participation outlets) and also a sense of uncertainty. This was true of both the DwA and AwD groups.

Plans for activities could be derailed by pain that fluctuated from day to day. Due to pain, Joan (aged 86,DwA) would like a new body. Janice (aged 66,AwD) interprets fatigue as her body telling her she cannot do something:

> Janice (AwD): My mind is willing but my body is not able.….. when I stand up to try and do something my body just is just telling me, ‘you can't do it’.

Suffering and sadness was associated especially with pain, experienced at all ages and stages and with different disabling conditions. A few people experienced a state close to despair because of pain. Thus, for most participants there is no denying the centrality of the body in everyday life (Whitaker 2010) and there is no denying the high degree of suffering that bodies caused to some. Gilleard's (2018) suggestion that gerontology must witness and document the suffering that many older people experience, is similar to Wendell's (2013:171) argument (from within disability studies) for acknowledging the existence of 'suffering that justice cannot eliminate'. Participants' experiences are consistent with post-social model or critical disability studies (including the feminist scholars quoted at the beginning of this Chapter) who argue that impairment has its effects, even if that is not the whole story (see also Shakespeare and Watson 2002). And, indeed, impaired bodies were not the 'whole story' in terms of how participants experienced disablement, as **Chapters 8** and **9** will show.

For some, bodily experience was understood as gradual 'decline' relative to earlier life. Others told 'catastrophic' narratives – where disability was related to a single event (such as an accident or stroke).[57] There was also some overlap, as people who initially experienced a 'catastrophic' onset and had lived with impairment over time might employ a 'decline' narrative on top. It is not surprising that participants identify with framing of disability that emphasises bodies in line with the medical model (see McGrath *et al.* 2017). But a small number of males, mainly in the AwD group, experienced bodies as not (or minimally) disabling – impaired, yes, but not disabling. In some respects, they resembled the comparative sample of participants who were not disabled.

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[57] Incidentally, this is consistent with how the process of ageing into disability is known to occur - through the sudden onset of a disability-causing condition or through slower advancement of symptoms that may result from other health conditions (Naidoo, Putnam and Spindel 2012). Likewise, Ferrucci *et al*. (1996) made distinctions between progressive and catastrophic disablement, with older age associated with increased risk of both.

7.2.1 Perceiving 'Decline' (or 'one can't hope to be any better at this age')

Participants associated gradual bodily 'decline' with a natural process of ageing; they talked about it relative to earlier functioning and saw it as 'normal' and irremediable. They were often vague about when changes started, improvements were largely not expected; they linked the experience to finitude. This experience was typical of the oldest participants from the DwA group who experienced gradual onset of impairment for the first time in older age, and also of AwD participants who perceived 'decline' in functioning *in addition* to long-standing impairments. Thus, 'decline' linked to a sense of finitude was a key *meaning as significance* (Bury 1988) that participants made of their experiences.

Terms used included 'deterioration', 'decline', 'wearing out' or 'going downhill'. Teresa (aged 87,AwD) went from walking with crutches to using a wheelchair in her 70s and at the same time her eyesight worsened. She says that there are a lot of things she cannot do now and describes how her eyesight has gone gradually: 'just by degrees, I couldn't say when it really went'. Colin (aged 88,DwA) used the terms 'deterioration' and 'wearing out' to describe changes in his eye-sight and perceived these changes as 'natural'. Gloria (aged 80,DwA) said:

> Gloria (DwA): But anyhow one can't hope to be any better at this age, one is not going to get any better.

Thus, participants – especially those who were oldest - perceived their time of life as 'on time' to be functionally limited, pointing to the intertwined constructions of ageing and impairment and how social constructions of age and the lifecourse affect meanings they make of disability (see Kelley-Moore 2010). As Bury (1982) says, the search for the cause is 'at one and the same time a search for its meaning'. Being older meant that a link to finitude was a key meaning they gave to impairment.

Gradual experiences of disablement could also involve points of crisis and sudden change: there were times when 'decline' really manifested or when things changed for the worse. For example, Gloria (aged 80,DwA) described starting 'to crumble' in her 70s, followed by a fall which made things very much worse leading to a period of hospitalisation and ongoing pain. This could be true of the AwD group too, as functioning might be perceived as static for years, but ageing brought gradual changes punctuated by dramatic events. Teresa (aged 87,AwD) found her ability to walk with crutches changed suddenly one evening on an outing with a local group. She required a wheelchair afterwards. Tony (aged 83,AwD) described a gradual 'deterioration' in his legs followed by a sudden worsening when he fell in a spectacular accident while helping to officiate at Mass.

For the AwD group, additional impairments could make functioning very difficult. For example, Hazel (aged 80,AwD) experienced visual impairment first in her 30s. In recent years the experience of severe hearing loss has come on gradually. Hearing loss is isolating and she finds it more difficult than visual impairment:

> Hazel (AwD): If I had a choice between the two, if I was going to get one of them back I would prefer to get my hearing back because you can't communicate at all without your hearing. Your eye-sight you can manage, but hearing is most important.
> Interviewer: And what is that like, not being able to communicate with people?
> Hazel: It is so…you are so alone.

She describes getting older as 'difficult and not enjoyable' and she feel less independent – in that respect, she perceives that her experience resembles other older people. But she also feels more isolated because she cannot compensate for hearing loss by lip-reading and, therefore, social occasions have become difficult and she sometimes avoids them.

Some of the youngest participants in the sample who were in the AwD group perceived 'decline' or ageing before-time, long before their 60s. Thus, for those experiencing progressive conditions and others, 'decline' could be their experience for decades. For one, onset of a stroke in her early 40s had been 'an old person's stroke' (by which she meant it was severe). Some perceived that conditions associated with ageing (like arthritis) made existing conditions worse or they were not sure whether symptoms were due to age-related conditions or to an existing condition. Thus, for this group bodily changes were sometimes linked to ageing, or to time advancing, and also to the progression/worsening of conditions.

The experiences of the AwD group suggest ongoing change, sometimes accelerating with ageing, consistent with findings from empirical studies with this group (see **Chapter 3**; Zarb and Oliver 1993; Jeppsson-Grassman 2013; Jeppsson-Grassman *et al.* 2012; Simcock 2017). Thus, despite many similarities with the DwA group, there is a sense – obvious as Hazel describes loss of hearing compounding the difficulty of being blind already – of a kind of double jeopardy with ageing for the AwD group (see Reyes 2009; Bishop and Hobson 2015; see **Chapter 3**).

Finally, even where there was alignment with a 'decline ideology' (Gullette 2004:130), this did not mean that participants were fatalistic in how they responded or that they defined themselves by their bodies. For example, Gloria, who identified strongly with a 'decline ideology,' continued any activities she could – as a volunteer with meals-on-wheels (doing it now sitting down), attending a painting class, looking forward to having grandchildren to stay and so on. Patricia (aged 90,AwD) described the activities of her week as attending daily mass and being collected to go to an older person's day care centre one afternoon per week. Additionally, she occasionally takes a taxi to go to the concert hall. Yet her perception of herself is of an active person 'do[ing] everything':

> Patricia (AwD): I just get out and do everything, go anywhere, go to the concert hall, anything that is going and that is it.

Patricia's framing of her approach is evocative of descriptions of the third age or successful or active ageing – focused on social and leisure participation – and does not align with more passive or disengaged framings that might be associated with the fourth age (see Laslett [1989]1996)).

7.2.2 Perceiving 'Catastrophe' (or 'that put paid to everything')

A second group experienced sudden or unexpected onset of disability for a variety of reasons, including stroke, accident or onset of a progressive condition. They did not necessarily link impairment to chronological ageing or finitude – although that varied. Onset tended to be experienced as unanticipated, causing a crisis requiring a great deal of adjustment often following lengthy hospital stays. Amongst participants, this was experienced at a range of ages, including in their 80s, though most experienced it earlier. They tended to narrate their disability experience by recalling an event - the 'stroke', 'accident', or condition-onset and with a consciousness of experiencing a major change or turning point and a strong contrast between life before and after. These experiences were not confined to the DwA group or to those who experienced adult-onset, as those with lifelong disability could also experience points where life took a different direction when bodily conditions significantly worsened.

These events were described as life-changing. James (aged 83,DwA) used a defining phrase of a stroke experienced in his 80s: 'once you get the stroke, the rest is history'. This was typical of how participants recalled these events, with another saying that a stroke 'put paid to everything'. Many recalled the date, time and occurrence of a single event even if they didn't know its full import then. For example, Francis (aged 76,DwA) recalled a stroke at age 58:

> Francis (DwA): I'll never forget it. We were, it happened at night-time around nine o'clock. We were watching television and my foot went to sleep and I went down to the kitchen. We were in the sitting room and I went out to the kitchen and I thought the feeling would come back into it and it did. And my wife came down and she said, 'Is there something wrong?' I didn't want to worry her and I said, 'My foot went to sleep.' So anyway, she knew there was something wrong. We went to bed and next morning, my foot, I had very little feeling in the leg and all. [talks about trip to hospital]….. I was there for a while, for a few months and then I came home. They taught me when I was there, they taught me how to walk which is a bit unusual when you're used to walking all your life.

At another point Francis talks about his 'past life' and says that his life now feels like a totally different life – one that he said he couldn't have imagined to the extent to which he is not able to do the things he used to do like farming, driving or DIY. At the same time, Francis shows a consciousness of continuity – describing himself as having had to give up being an 'active' farmer – in other words retaining the identity of 'farmer' while having had to let go of the activity of farming. This can be seen as bracketing off the impact on him to preserve the sense of a valued identity. Somewhat similarly, Carmel (aged 69,DwA) points to many things she cannot do since an operation that removed her legs, but says that she doesn't feel differently about herself – she still thinks of herself as a ‘decent’ person. Thus, participants exhibit a sense of identity that is simultaneously continuous with the past and different too because of a ‘changed condition’ (Holstein 2015:118).

Sometimes, on top of initial impairments, these participants perceived a more gradual ‘decline’ associated with ageing. For example, Francis describes a series of problems (‘mini strokes’, falls and fractures requiring him to eventually use a wheelchair) since his initial stroke. He used the term ‘going downhill’ and links being 76 with a time to ‘start slowing down’. Thus, he now interprets his ongoing experiences in terms of ‘normal’ ageing and links it to a sense of finitude.

Some accounts of sudden onset were instructive in relation to implications for identity of interpretations of positive socio-cultural discourses of ageing. For example, Annette (aged 84,DwA) talked about always having had excellent health until she experienced sudden onset of illness resulting in activity limitations in her early 80s. For her it was life-changing:

> Annette (DwA): So I suppose I had fabulous health up to that Christmas, Christmas of 2014 and then the whole bottom fell out of my world….. And the shock of that nearly killed me because I was never sick. Still I suppose it catches up with us all soon or later. And like [Coordinator of Older People’s centre] always says age is only a number, and I always had that outlook in life, age is nothing, it is how you view yourself that counts in the end. Oh well, that was it.

One of the key consequences related to her role in her local older people’s centre, where she sang and used to be ‘the main dancer’ and she greatly regrets not being able to participate now. Annette’s interpretation intersects with concepts like positive/successful ageing, describing her pre-illness belief that ‘age is just a number’ and that it’s ‘how you view yourself that counts in the end’, typical of the psychological resources associated with these discourses (see Timonen 2016). Annette refers to this to explain why she experienced shock when her health and functioning changed; her belief in these concepts contributes to her perception of the event as shocking and almost as of out of time. It is as if adherence to positive ageing approaches contributes to her perception of this event as unanticipated in biographical terms and highly disruptive. Thus, the focus on youthfulness in these discourses and the way they extend middle-aged lifestyles into older age may, for those who invest in them and who experience good health into older age, contribute to making onset of chronic illness and impairment seem biographically disruptive, even in the classic Buryan tradition of an unexpected event in an otherwise healthy life. Clearly, this also challenges the proposition from Williams (2000) that being older might make onset of chronic illness biographically *anticipated* rather than disruptive.

Annette now appears to experience a tension between her bodily experience and the socio-cultural discourses of positive/successful ageing. The ambiguities involved are evident at another point, when Annette indicates that this onset is tantamount to sudden onset of ageing: ‘I had to give in and admit I am getting old [laughs]’. Thus, she and other participants link impairment-onset with being ‘old’ and continue to engage in processes of social identity formation that, as Hockey and James (2003:12) suggest, is ‘inevitably incomplete.’

Participants who experienced disability onset in adulthood often perceived broad consequences due to its timing – say when children were young, and giving up work could be perceived as a point when the implication of a condition crystallised. For example, Blanad (aged 61,AwD) experienced onset of Parkinson’s Disease at age 30 and started her narrative with that experience:

> Blanad (AwD): Well. I’ll start when my life changed. And that was at the age of 30. I had two children. And I was a primary school teacher. And I began to feel very unwell and unable to keep up in the profession. [talks about the effects of symptoms, diagnosis and about medication and its impact over several years]…. So I had to come out of teaching. And that was devastating to me. So that was kind of the real changing point in my life and changed my whole perspective and my whole relationship with people in life because I became a dependent person in certain situations. And my husband then became kind of the mother at home

She identifies giving up teaching as the real ‘changing point’ – when relationships and her ‘perspective’ changed and she became a ‘dependent person’. She had to rely on her husband and others for help with her children. She described the worst thing she experienced in her 30s and 40s as having no ‘identity’ outside the house or outside the diagnosis of Parkinson’s.

Though different individuals draw on different resources to negotiate among different later life social identities (in the way that Hockey and James (2003:11) suggest), for all of these participants, sudden or unexpected disability onset provokes a shift in social identity and roles. These accounts are very similar to how Bury (1982;1997:124) characterises biographical disruption of the taken-for-granted, involving a potentially damaging loss of control and altered social relationships. However, for many participants these experiences were not single or isolated ones – and worsening impairment, further challenges and identity questions could follow. For example, Sheila (aged 61,AwD) who first experienced MS in her 30s and now uses a wheelchair described being taken aback in recent times at hearing a nurse refer to her a ‘paraplegic’ – decades after initial impairment onset, this categorisation bothered her as it hadn’t occurred to her up to that point that her functioning was that restricted or that that is how others perceive her:

> Sheila (AwD): I kind of felt, am I really? You think you are managing but other people know you are not managing.

Lifelong disabled participants too could experience significant changes in adulthood associated with worsening conditions and could continue to experience disruptive changes as they got older. For example, Helen (aged 68,AwD), experiencing disability since childhood, worked and lived alone, but had to move in with family members when her condition worsened around age 40 – a point she perceives as a turning point (‘I took a different course then’). The fact that she perceived it as a threat to her sense of identity can be seen in how she tried to minimise its effects at that time by concealing some of the challenges of impairment from work colleagues – specifically the fact that she needed to be connected to an oxygen machine at night. She said that concealing this meant that she felt that she had ‘led a double life.’ She subsequently adjusted to the new situation and now lives on her own again, but another significant change has come within the past two years since she has to carry around an oxygen tank at all times. She said that it is only since this change that she has really felt disabled – both identity management and daily life is now more difficult - and she now is anxious about maintaining her ability to look after herself in the future.

Similarly, April (aged 65,AwD) described a period in her early 40s when she started to experience the effects of post-polio syndrome as confusing and difficult, involving pain, fatigue and especially challenges in looking after herself and her children. She described how she experienced the change to using a wheelchair:

> April (AwD): The first year I hated it [wheelchair]. I used to sit in the corner, reversed into the corner in the sittingroom. I'd be staying like this watching the television but I wasn't watching the television. I was miles away but I was staring at the screen.

April perceived this as an assault on her sense of identity though it came in a lifecourse highly affected by having experienced impairment as a toddler (involving childhood largely spent in hospital followed by exclusion from her family who sent her to an orphanage, aged 12).

There was a small number amongst the AwD group – especially people whose experiences were of severe disability and input by carers throughout lives that were partially lived in residential care - who, even though they experienced (and continue to experience) frequent health issues and challenges and increasing/new impairment, seemed to take them more for granted. For them their past experiences perhaps mediated the experience somewhat. Thus, the AwD experience was heterogeneous. But for most AwD participants, experiences in adulthood and continuing into older age involved and continue to involve complications and bodily change and associated fear, uncertainty, possible fundamental change in social lives and greater dependence – even if people are living with support already, they fear losing the independence they have.

To summarise, the discussion to this point, for those who experienced relatively sudden onset of impairment, their experiences resemble how Bury (1982;1997) characterises biographical disruption of the taken-for-granted. However, they were not always single events that happened in lives untouched by bodily challenges prior to that. And even where they were, initial onset could be followed by further impairment, complications and challenges to a sense of self. For most participants, the experience was characteristic of the incremental cycle of adaptation that Charmaz (1995) describes and was consistent with how Larsson and Jeppsson-Grassman (2012) have expanded the concept of biographical disruption - that it can involve a series of disruptions over the life span and does not have to be a single, wholly unanticipated event.

Whichever onset narrative participants employed, they could perceive older age as ‘on time’ to be functionally limited (or to experience ‘decline’), and thus social constructions of age and the lifecourse affected meanings they made of disability. This did not mean they defined themselves wholly by their bodies, and, in a seeming contradiction, this was also compatible with continuing to identify with aspects of ‘successful’ ageing or third age approaches. But it did mean that many of them could employ a discourse on ageing (‘decline’) with which to interpret experiences and it enables them to perceive what they are experiencing as ‘natural’ or comprehensible – thus, it enables them to construct a reasonable level of explanation, which may mitigate the experience of disruption (Bury 1997:125). In Bury’s (1991:461) terms, they learn to cope or to maintain a sense of value and meaning in life. It can be seen as an attempt to impose control, in the sense of interpretive control or comprehensibility, on experience.

Thus, in response to a high degree of change and loss, they are trying to interpret their lives in a way that makes sense of existence and attempting to lead a life perceived as meaningful (see Stillman *et al.* 2009; Derkx 2013). The changes they experienced means they were often trying to remake their lives in ways that made sense of them. I expand on this argument in **Chapter 9.**

7.3 Bodies Experienced as Impaired but not ‘Disabled’: (or ‘the only change…..would be ….the fact that I'm retired, but I'm much busier now’)

In contrast to all disabled participants in this study, a small number of males from the AWD group felt that their bodies did not disable them, or disabled them slightly but caused little difficulty. For this group, impairments had been experienced as relatively stable from birth or from early-life. They had experienced minimal, or no, changes in functioning with ageing or with the passage of time. This sets them apart from the other participants in this study other than the sample of non-disabled people.

For example, Len (aged 69,AwD), a wheelchair-user following an amputation in his teens, feels that impairment causes him no difficulty – pointing to how he drives an adapted car and lives in an accessible house. In answering Census questions on disability, Len identified as having a condition - an issue with mobility - but said it caused him no difficulty. In fact, he answered all the functioning questions from the Census in the negative – (thus, no difficulty getting around his house, getting outside alone, participating in leisure). He was not ‘disabled’ in those ways. He perceived minimal changes with ageing in his body. Retirement was the biggest change of recent years.

Similarly, Desmond (aged 72,AwD), visually impaired from birth, stressed ceasing work as the biggest recent change. He likened his experience to that of any retired person, describing ways he keeps active since retiring at age 65:

> Desmond (AwD): Well the only change as I said would be the change in the fact that I'm retired but I'm much busier now. Retired with a disability? It doesn't make a difference to me because I'm still going. I suppose the problem is if you have a disability and you are working and you retire and you do nothing. That's where the problem comes in. So that applies to all people whether they have a disability or not. You must have something to keep the mind very active.

For Desmond, blindness is just how things are – he both uses the word ‘disabled’ of himself and says he never thought of blindness as a ‘disability’, by which he means that it didn’t stop him doing things. In recent years he has no ‘aches and pains’ and the only perceived change in functioning is gradual onset of hearing-impairment. He also perceives himself functioning closely with his wife. Now using hearing aids, he considers that his body causes him no difficulty:

> Desmond (AwD): Well you see hearing would be difficult if I hadn't got me trumpets [hearing aids] in. And me eyes - zero problem except I can't do the painting but sure that's no harm.

Both Len and Desmond experience disability at times due to environmental issues but these were mainly issues that were not new for them. Thus, Len referred to occasional difficulties with accessing parking or stairs, and Desmond found negotiating where he lives more difficult due to more cars, and he also felt angry about occasional obtrusive questioning from others to him or his wife about his visual impairment. In the main, these were issues that they had learned to live with (though they could still consider them unjust).

David (aged 72,AwD) was also blind from birth but differed from Desmond in describing blindness as disabling of itself – he felt it isolated him from people who didn't know how to engage with him. In this way, he is similar to post-social model disability scholars who argue that barriers they experience cannot be regarded as either 'entirely socially produced or amenable to social action' (Corker and French 1999:4). However, like Len and Desmond, David has experienced no change in his body in recent years; being blind causes him no difficulty in day-to-day activities, because he is used to it. Thus, while he considered himself 'disabled', he answered 'no' to all the functioning questions from the Census questionnaire. And his narrative placed a large emphasis on the physical activities he engages actively in - tandem-cycling, running and skiing. Of retiring he said:

> David (AwD): I didn't mind retiring at all. I just felt it was another chapter closed and I had the prospect of joining the gym and walking and a couple of cycles a week so I had a full enough programme to look forward to.

These experiences resemble some participants in Jeppsson-Grassman's (2013:30) study with lifelong disabled people who were living 'rather active 'third-age lives' and were like 'any retired person'. Their experiences resembled some of the non-disabled sample in this study – in the sense that bodies were largely taken for granted. Thus, the focus on activities for these participants resembled the similar focus from some in the non-disabled sample (ND). For example, Maura (age 66,ND) said:

> Maura (ND): I'm quite, I'm looking forward to the rest of my life. Age never made any difference to me. …. I, we have plans now for this year, you know to go out foreign and I'll be going out to Spain to my friends. I'll be going with my two girlfriends over to Spain as well, later on in the year.

Thus, the accounts of Len, Desmond and David, might tend to confirm the thesis that lifelong disability builds coping skills and resilience that helps people to cope with older age (Reyes 2009; see Iwakuma 2001), in contrast to the double-jeopardy theory discussed already. Similarly, in terms of the biographical disruption literature, their experiences might at first glance seem to support the assumption of Williams (2000:50) that this experience might be one of continuity *not* disruption. However, for these participants, *and at this stage in their ageing process*, there do not appear to have been notable health or additional impairment challenges in recent years – thus, there has been no biographical disruption. The stability of the bodily conditions that these participants experienced, and the fact that at this stage they have experienced minimal changes with ageing, appear to be factors that set their bodily experience apart from other disabled participants.

Given that all the participants in this category were men, it is possible too that there is an element for some of playing down difficult bodily experience to avoid expressing loss or sadness in a culture that values ‘toughing it out’ (Becker 1998:11). Given that they had all worked and some had public sector pensions, their material resources or class (they were all middle-class) probably also played a role in these perceptions, particularly having the resources to deal with restrictions in environments (for example, Len drives an adapted car).

7.4 Consequences: Having a Heightened sense of Uncertainty, Activity limitations and Participation-Restrictions

As is implicit from the previous sections, participants who perceived bodies as disabling perceived their direct consequences in terms of what they could not do in their lives. These consequences were felt as part of an ongoing, dynamic process involving a sense of uncertainty about day to day life and the future, activity limitations and participation restrictions. Participants were often highly exercised by these consequences – especially having to let go of activities/occupations, and they were often sad and concerned about their lack of control over events.

7.4.1 Having a Heightened Sense of Uncertainty (or 'one little thing and you're gone over the edge')

Participants used a range of expressions related to activities or participation that expressed the provisional, dynamic nature of the experience. They talked of things they were doing using terms like 'still,' 'as long as' or 'at the moment' signaling perceptions of contingency. Typical of Irish culture, phrases like 'please God', 'thank God' or 'touch wood' were used in relation to things that could still be done. For example, talking about going out alone using his rollator, Paul (aged 69,DwA) said:

> Paul (DwA): Take my time and carry my mobile phone in case I get into trouble. So far, I haven't, thank God.

In addition, pain or fatigue could increase/decrease, causing precarity about activities and participation. For example, Janice (aged 66,AwD), who experiences periods of extreme fatigue, says she prefers not to 'make plans' for the weekends because 'something always goes wrong … so I just take the ball on the hop and just go for it'.

A sense of precarity in functioning was evident in references to falls and to fears of falling, which were common across interviews, as was the sense that a fall might change everything. For example, June (aged 82,DwA) describes being 'wary of falling' and of her legs going 'from under me.' She adds

> June (DwA): It is always in the back of your mind when you get to my age.

For the AwD group, the precarity I describe here could have characterised their whole lives – thus, a fear of falling or a sense of vulnerability – or of being seen by others as vulnerable - could have been part of their experience at any age, something often worsening over time. For example, Simon (aged 66,AwD), visually impaired since childhood, said that visual impairment always made him feel 'vulnerable,' as that is how he thought others would see him. Talking about falling, Blanad (aged 60,AwD) said:

> Blanad (AwD): You know I've always fallen so many times trying to get through a crowd. If somebody just turns and brushes against me, I start falling and I can't recover my balance.

Their accounts suggest that a ‘permanent state of uncertainty’ associated with being older and impaired (Grenier 2012:177) can also apply at younger ages for disabled people (Mattlin 2016).

When participants talked about the future, it involved precarity about living arrangements associated with anticipated decrements in health and/or functioning. Some thought that current living arrangements were unsustainable and they spoke with sadness about this. Several considered that a nursing home was the only option, sometimes not perceived as very much in the future, although its timing was unknowable. Thinking about the future caused suffering for some, and not every participant found it easy to discuss. James (aged 83,DwA) wept at the thought that his health might change and he might become a ‘burden’:

> James (DwA): Well thank God and his Holy Mother, because I dread I should get sick because I would be a huge burden on [daughter] and anybody else. There is nobody else and I am totally dependent on her [weeps] and she is so good. [Pauses] My health, thank God, is holding up.

Participants often referred to having no control over what will happen. Helen (aged 68,AwD) fears a period of not being able to care for herself (which she distinguishes from needing some support with self-care and housework at present) or being confined to bed, and hopes ‘that God will be good to me and he won't do that to me’. For Helen and others, talking about death was not as difficult as thinking about greater dependency, something she cannot control:

> Helen (AwD): I think how my health is going to deteriorate and what way it will go. It can't deteriorate much more than it is [little laugh]. Yea of course it is a big concern. But there is no point, you can't control it.

Thus, even though Helen has lived with disability since childhood, and worsening disability, pain and inconvenience from her early 40s, she is concerned about the situation at present and about the future. Her fears fit with Bury’s notion of biographical disruption, involving the prospect of increased dependency with its implications for relationships, and ‘re-thinking of the person’s biography and self-concept’ (Bury 1982: 169). However, as I argued already, this experience is broader than the Bury conception, as it was not a single event and not necessarily an unanticipated one, and, in that respect, Helen's experience is consistent with how Larsson and Jeppsson-Grassman (2012) have expanded the concept of biographical disruption.

Others like Tony (aged 83,AwD) talked about the prospect of moving to a nursing home as virtually inevitable and felt they could not control it. Francis (aged 76,DwA) feels he may have to move to a nursing home if his wife's functioning deteriorates:

> Francis (DwA): When I get more infirm, I'm just wondering what will happen. I know that I'll end up in a nursing home in the future, whether a couple of years or longer. But that's life. I can't do anything about that.

An awareness of finitude was made explicit by some, suggesting a sense of existential precarity. Julie (aged 80,DwA) talked about fears of her functioning disimproving, fears for her husband's health and for what that will mean for her living arrangements. She also talked about a general sense of precarity associated with ageing which she described as 'being on a knife's edge'.

Some participants drawn from the non-disabled ('ND') sample were also concerned with finitude even if they didn't relate this to changes in their bodies. For example, Betsy (aged 78,ND), said:

> Betsy (ND): I suppose getting to this stage of my life I think about what is going to happen, pass away and all that sort of stuff comes into my head.

But for the disabled group, having already experienced threats to health and functioning seemed to contribute to a heightening of this perception and to a greater sense of uncertainty. For example, Julie (aged 80,DwA) who said that ageing was like 'being on a knife's edge' also said:

> Julie (DwA): I never think nothing else is going to happen to me now because it could.

This suggests that challenges to health and to functioning are significant benchmarks for conferring meaning on the process of growing older. As

Hockey and James (2003:153) suggest of onset of illness, this is because it, rather than bodily changes *per se*, ‘prefigure[s] death and the end of life’

Others said that they did not think about the future and some even think it is dangerous to do so in the sense of endangering mental health. Several said they concentrate instead on living in the present. Some felt they had lived to ‘a good age’ (Patricia, aged 90,AwD) and wondered when death might come, but nobody knew when. They sometimes tried to understand this – to make it comprehensible or impose meaning on it - by reference to the length of time that antecedents lived. For example, Colin (aged 88,DwA) says:

> Colin (DwA): I think I am at the last stage [of life] but I have no idea how long the last stage will be because my parents both lived to over 90 and my grandmother lived to 102, so who knows.

Thus, there may be a short event horizon and a strong awareness of finitude – but that too tends to involve uncertainty, because even amongst the oldest no-one knew when death might come. These participants are expressing the contingency that is part of being human, but it is also related by them to their stage of life and to their consciousness that time is finite. They experienced what Baars (2010:116) describes as ‘the vulnerability inherent in human life [which] radicalises as people get older’. This increase in a sense of vulnerability is a factor in perceptions of life as less meaningful and in efforts to reconstruct the meaning structures of their lives – or to remake lives that make sense - the overarching conceptual category of my analysis. I discuss key ways in which they tried to do so in **Chapter 9.**

7.4.2 Losing Activities and Participation Opportunities (or ‘I can't read because my eyes are gone but I get the audio books’)

For participants, another key consequence of impairment or a disabling body involved change and loss in respect of everyday activities and participation outlets and associated confinement and mundanity. In fact, this was *the* key way in which they understood the impact of bodily changes, whether involving impairment onset or worsening. Thus, bodies allow us to act, to intervene in, and to alter the flow of daily life (Shilling

2012:12) and changes in bodies or functioning may hinder us in doing so. Bodily change was the key reason for these losses as they perceived it, although several perceived themselves as also excluded by environmental barriers or prejudice of others, as I discuss in **Chapter 8**, so this too forms part of how the experience is perceived as disruptive of the sense of self.

Participants responded to the challenges involved. In **Chapter 9**, I will discuss a range of ways in which they responded – including investing everyday activities with new meaning and maintaining and taking on new activities. Here I focus on only some of those responses - how they made efforts to maintain functioning (although often ambivalent about what was possible) and often also shifted to focus on what they could still do, and how they could also play down consequences of impairment (or worsening impairment). These can be seen as efforts to cope and tolerate their impairments by trying to minimise symptoms (through efforts to improve functioning), and by bracketing off the impact of impairment so that the effects on identity were minimised (Bury 1991). All of these efforts to cope represent, I suggest, seeking to live lives they value and have meaning, which is the key argument of this thesis.

As is implicit in the accounts included above, participants had to give up jobs and professions or valued roles in community groups due to disability onset (or worsening). The range of activities and roles that had ceased to be available or accessible was broad – reading, watching TV, holidaying, volunteering, walking/hiking, sports attendance/organising, card-playing, participating in arts/cultural activities - often activities that involved socialising and lives linked to others. Some perceived risks to their mental health (through depression) if they didn't find ways to occupy themselves or get out of the house. Several contrasted busy, sociable post-retirement phases with quieter, more confined times now. All these changes could be associated with sadness, loss and greater confinement to home, and with losses of social identities and challenges to the sense of self.

For example, Stephen (aged 88,DwA) points to how he has had to let go of a leadership role in his local community – something that he had taken a lot of pride in. He says 'I am not the [Stephen] that was' – though he also maintains community activity where he can and perceives some continuity through this. Other, less community-based activities, were also understood as involving significant changes. Women, in particular, who took pride in their home-making, regretted cooking/housework being difficult or impossible. Men, in particular, talked about no longer being able to do DIY jobs around the house. This could be thought of in identity terms. For example, Paul (aged 69,DwA) talked about how he used to be ‘a great DIY man’.

Giving up driving was mentioned by several as a significant point (not always coinciding with initial impairment onset) when they realised that their life had changed, described in terms of a loss of independent functioning or freedom or in the context of having become more dependent - as a blow to a sense of identity as an autonomous person. For example, Francis (aged 76,DwA) talked about having had to stop driving an adapted car in recent months (many years after his initial stroke) as follows:

> Francis (DwA): …. I definitely regard it as a big moment that I said oh, ‘Jeez, I can’t go there or I can’t go here’.

As I argued already, these participants continue to be involved in processes of identity negotiation, which remains ‘inevitably incomplete’ (Hockey and James 2003:12). One of the ways some participants responded involved activities to maintain or improve functioning. For example, without a great deal of confidence in its efficacy, James (aged 83,DwA) uses a device to exercise his legs, and Tony (aged 83,AwD) refers to efforts to try and maintain functioning: ’I do exercises to try and keep yourself kinda right’. This was so notwithstanding associating bodily conditions with advancing years, and perceptions that improvements were unlikely in an overall sense. This was summed up in Annette’s (aged 84,DwA) comment:

> Annette (DwA): But please God it will cure itself and I will get back to normal. But then again I am getting older, I am 84 now, I was 84 after Christmas so I can't expect...[pause]

Thus, a sense of finitude was ongoing especially for the oldest participants - making the experience highly ambivalent, balancing attitudes of pragmatism and acceptance with hopes and efforts to maintain or improve.

And participants often moved quickly from describing something they could not do to focus on what they could do and resisted being defined by what they could not do. For example, Stephen (aged 88,DwA) pointed to how he is still involved to an extent in local groups and how the people involved still ‘respect’ him. And, Teresa (aged 87,AwD) has become visually impaired gradually with ageing and cannot read, something she loved, but she adds immediately that she makes up for this by getting audio books: ‘now I can't read because my eyes are gone but I get the audio books’. Janice (aged 66,AwD) accepts that she cannot change the way her body is and moves to a focus of what she can still do, focusing on being ‘still independent’:

> Janice (AwD): I have gone a little bit downhill now but it's not getting me down because I'm still independent. I'm able to shower meself, feed meself, cook. I'm able to do all the basics within reason.

Related to both focusing on what could be done, and with accepting ‘decline’ as inevitable or ‘normal’, was a sense that participants sometimes played down the consequences of impairment. Images of the lifecourse can cast some actions as appropriate and inappropriate (Holstein and Gubrium 186). Thus, images of the lifecourse reflected in participants’ perceptions that impairment was ‘on-time’ may reinforce the idea that it is appropriate to minimise reactions to impairment in older age. A related factor is how ‘coping’ or ‘managing’ implies moral worth in western culture (Tanner 2010:182). Whatever the reasons, as part of an effort to cope, participants normalised and bracketed off the impact of illness so that the effects on identity were minimised (Bury 1991). Thus, while loss and suffering were expressed about changes in functioning, there was sometimes also a sense that they did not want to dwell on this. Both are evident in what Tony (aged 83,AwD) says:

> Tony (AwD): You haven't got the physical, the physical exercise or walking facilities, running facilities that you had we’ll say six years ago. And you think about it and it takes you back a bit, but sure you are then resigned to it and that is life, life goes on and you have to accept these things [sighs]

Thus, participants could alternate between talking about the consequences in their lives as severe, and comments which seemed to play down the significance of such consequences. Overall, there is a sense of encompassing new aspects within an existing sense of self, and making the best of how life is now, even though that involves accepting limitation, loss and finitude.

I return to the issue of responses to losses of activities and participation opportunities in **Chapter 9**. There I will focus on further ways in which participants reacted to those losses (and losses of intimates) in ways that involve attempts to restore ‘order following disruption’ (Becker 1998:4), or to maintain a sense of value and meaning in life (Bury 1991:461).

7.5 Discussion

In this Chapter I described and discussed how most participants experienced disablement through bodies that limited what they could do, and many also experienced bodies that caused them pain and/or fatigue or balance issues. Thus, bodies caused some participants a high level of suffering. My approach is consistent with an identified need for critical gerontologists to witness and document the suffering that can be part of ageing (Gilleard 2018) and to engage with the ‘real bodies of older people’ (Holstein and Minkler 2007:16).

For most participants, the impaired body (or bodies that limited them or limited them more) was the key way in which they experienced disablement. Given the dominance of the body in biomedical accounts of ageing, this is hardly a surprising finding. Less well-recognised are their interpretations of their experiences. The consequences they perceived included suffering, loss and (for many) a sense of finitude, uncertainty about daily life and the future, loss of a sense of autonomy and forced abandonment of social activities and roles. I show that all of this can involve a fundamental re-thinking of biography and self-concept and was associated with the ongoing negotiation and renegotiation of social-identities. Even when disablement occurs at a stage in life when it is considered – by the people concerned - as ‘normal’ or ‘on-time’ – it can create a sense of disorder requiring efforts in response. This goes against the assumption of Williams (2000) that the normative connection between impairment and older age might make onset of chronic illness an *anticipated*, not disruptive, occurrence.

‘Decline’ and ‘catastrophe’ were common interpretations of the experience of disablement. ‘Decline’ narratives were typical of participants experiencing gradual disablement amongst the oldest participants (DwA and AwD) and associated by them with a natural process of ageing and finitude. But even where there was an identification with ‘decline’, participants did not surrender to this, and they did not define themselves by their bodies. They focused on what they could still do and often made efforts to both improve functioning and to maintain pastimes, connections and activities where they could. They tended to manage to maintain a sense of identity different from but also continuous with the past. They drew on different resources to negotiate their social identities, sometimes continuing to identify with successful/positive ageing discourses in-so-far as they could, which could introduce tensions and ambivalence. I suggest that through their various efforts to cope they were seeking to live lives they value and have meaning - the key argument of this study.

‘Catastrophic’ narratives of disability onset perceived as unexpected or sudden could be experienced at any point in the life span and could be mingled with narratives of ‘decline’ over time, suggestive of meanings changing as they ‘interact with different stages of the life course’ (Bury 1991:453). Participants’ narratives of ‘catastrophe’ clearly evoked Bury’s (1982) original concept of biographical disruption of the taken-for-granted followed by mobilisation of resources to respond – and this was true even amongst participants experiencing sudden onset in their 80s. For some, adherence to positive ageing principles contributed to the sense that impairment onset was disruptive in the classical Buryan sense of a single event in an otherwise healthy existence. But, for these participants, further challenges and cycles of adaptation could follow – and that is why the concept as expanded by Larsson and Jeppsson-Grassman (2012) is more relevant.

Even for participants for whom disablement had been gradual, it could have serious and disruptive consequences. Gradual change could also challenge a sense of self as an autonomous person who acts in the world – even if there was not one point identified where this had happened. It could involve a sense of not being able to control things and cause valued social roles and activities to have to be abandoned forever. Sometimes also experiencing pain or fatigue and concern about a future they couldn't control, participants experienced 'the unravelling of lifelong competences,' and inability to fully perform normatively valued activities/roles, challenging 'core identity as a full adult person' (Luborsky 1994:239,242). And I will show in the next Chapter that perceptions of exclusion and othering due to impairment onset (for the DwA group) also contributed to experiences of disruption.

Thus, I suggest that the consequences of disablement (or worsening of disability) were considerable - even when participants' interpretations of ageing and the lifecourse meant that they perceived disablement processes as 'on-time' or as part of a 'natural' process of 'decline'. Thus, impairment onset or worsening could both reinforce the biographical identity of older people *and* result in the simultaneous experience of disruption of biographical identities. Again, for these participants (experiencing gradual onset), the experience was consistent with how Larsson Jeppsson-Grassman (2012) extend the concept of biographical disruption (not necessarily wholly unexpected or a single occurrence). My findings are consistent with some condition-specific empirical studies with older people. For example, Sanders and colleagues (2002) suggested that participants could view symptoms of arthritis as 'normal', an inevitable result of their history and their older age *and* also experience disruption. And Meijering and colleagues (2016) found that biographical disruption could be experienced by older people as well as younger people (a study with people who had survived stroke[58]).

Disruption could be experienced by the AwD group (as well as the DwA group), as whatever lifelong competencies one had might be curtailed by further impairment, creating fears of greater dependence on others. For the AwD group, experiences of disruption could happen repeatedly across the lifespan and could worsen as time passed requiring repeated cycles of adaptation, each involving identity questions (Charmaz 1995). Thus, the concept of disruption was relevant to many of them also (as Larsson and Jeppsson-Grassman (2012) expand it).

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[58] As explained in a previous footnote, this study took a specific perspective on these issues, focusing on engagement with the rural landscape; thus they discuss biographical disruption/flow as bio-geo-graphical disruption/flow.

Over their lifecourses, these events could have involved consequences for a sense of identity involving a broad range of areas of life like employment, parenting and relationships. In this respect, the consequences that they perceived - at the time of onset/worsening – could be broader than for the DwA group, experiencing disability first later in life. This points to the need for a particular focus on the AwD group in public policies.

Consistent with this, I found, relative to theories about what the AwD experience might be (and discussed in **Chapter 3** -see Reyes 2009; Bishop and Hobson 2015), that worsening impairment with ageing, and new impairments, could represent a kind of double jeopardy, compounding difficulties functioning with existing conditions. However, the AwD group was heterogeneous and there were some who did not experience bodies as disabling – impaired but not disabling. They perceived their functioning as largely static for decades (or since birth) and ageing had not yet brought changes to health or activities – they experienced no biographical disruption. Rather than confirming the 'age-as-leveller' thesis (see Iwakuma 2001; Reyes 2009; Bishop and Hobson 2015), I suggest that they have not yet experienced the challenges, at a bodily level, that other participants experienced, and they took their bodies largely for granted in ways that resembled the non-disabled participants in my sample.

Participants used such discourses as were available to them to interpret their experiences, namely, master narratives of 'success' and 'decline' that have a fundamental role in shaping ageing identities and creating meaning (Laceulle and Baars 2014). Clearly, a 'decline ideology' (Gullette 2004:130-134; 2010) was particularly in evidence, but participants also evoked discourses of positive or 'successful' ageing – and both could exist in the interpretations of a single person. The emphasis on activity and self-realisation enshrined in 'successful' or positive ageing models seemed to resonate with many participants, perhaps more than is generally imagined (something I consider again in **Chapter 9**, arguing that this is because they wished to live lives they perceived as meaningful).

When participants invoked 'decline' with age, I suggest that they use it as a resource to 'impose meaning on threatening and seemingly arbitrary events' helping to mitigate disruption by providing a level of explanation (Bury 1982:175; 1997:125). Thus, being older could 'buffer' self-concept as disablement occurred (Kelley-Moore 2010:105). In this, they are trying to interpret their lives in a way that makes sense or to cope and maintain a sense of value and meaning in life.

But it may also have contributed to them playing down symptoms, wishing to be perceived as behaving in a way that was appropriate for their time of life. They may have been trying to be 'culturally appropriate' (Sanders, Donovan and Dieppe 2002: 246). Thus, there may be a cost associated with identification with a 'decline ideology' (Gullette 2004:134; Laceulle and Baars 2014); it may de-emphasise socio-cultural contributions (Laceulle and Baars 2014), and cause problems and suffering to be taken as things that individuals should accept with equanimity (see Jönson and Larsson 2009; Kane and Kane 2005). Pretending that disability does not increase with ageing (as reinforced by ideologies of successful ageing), or that it is the same thing as ageing and, therefore, 'normal' and to be accepted (as reinforced by a decline ideology) both have the effect of eliding bodily experiences. Thus, influential discourses may have reinforced individual level interpretations of participants and consequent isolation, as do public policies that reflect them.

Finally, these experiences are, I suggest, not unique to disabled elders; similar cultural concepts and ideals devalue impaired, disabled or ill people of all ages. Participants' accounts echo personal accounts of denial of bodily experiences by disabled people generally (see Luborsky 1994:247; Zola 1982,1991; Morris 1991). For example, it was only when Zola (1991) encountered disability activism that he could acknowledge bodily discomfort and realise that some of his experience was socially constructed. Discourses such as successful ageing occur within broader idealised notions of independent adulthood (Baars 2010; Lamb 2014) and prevailing concepts of autonomy and independence (Holsten 2015) and fears of human vulnerability. They are part of a culture in which both older age and disability are 'easily devalued' (Priestley 2001:246). I conclude that similar cultural ideals devalue both older people and disabled people and suggest that there is a value in approaches to scholarship, activism and other areas that address the lived experience of disabled people across the life span.

7.6 Conclusions and Implications

The findings discussed here show how participants experienced disablement (onset or worsening) in their bodies, meaning that bodies limited their activities and opportunities to participate, and sometimes caused pain and fatigue. This is not a surprising finding. But less is known about the subjective experiences involved. Participants could experience processes that involved a fundamental re-thinking of biography and self-concept due to onset (or worsening) of impairment related to a sense of finitude, uncertainty about daily life and the future, forced abandonment of activities and participation outlets, and fears of greater dependence on other people, all of which occasioned suffering and loss. These amount, I suggest, to biographical disruption even though they might not arise from a single event, as Bury conceived it, and notwithstanding participants' perceptions of impairment/disability, or 'decline', being 'normal' or 'on-time' in older age. But participants did not define themselves by bodily limitations and often emphasised what they could still do.

These findings also illuminate how two conflicting understandings of ageing in contemporary culture ('success' and 'decline') created tensions and ambivalences. Perceptions of 'decline' existed in parallel with efforts to maintain and improve functioning and a desire for connection and activity. I suggest that recourse to a 'decline ideology' may have buffered a sense of identity and helped impose meaning on seeming arbitrary and threatening events – as part of an effort to perceive life as having coherence or making sense in some way. They were trying to cope and maintain a valued self and a sense of value and meaning in life. However, both discourses - 'success' and 'decline' - may contribute to something of a denial of bodily experiences.

In this, participants' experiences were not unique to the experience of disability in older age, as denial of bodily experiences can be the experience of disabled people generally.

Concluding Remarks

In this Chapter I considered how participants perceived themselves disabled by their bodies, the first of two addressing the question of how disablement is experienced in older age. That bodies could disable or limit participants is not surprising. What the Chapter highlights is that they did not define themselves or wish to be defined by their bodies, and that even when disablement occurs at a life stage when they considered disability as ‘normal’ or ‘on-time’, it could also involve a fundamental re-thinking of biography and self-concept as well as loss and suffering.

Participants could be disabled by their bodies *and* by society, which is what I discuss in the next Chapter. I turn next to address ways other than bodies in which participants experienced disablement. I present findings that demonstrate that participants also experienced disability as a relationship between impaired bodies and the social environment.

CHAPTER 8: ‘AND NOW I AM THE ‘OTHER’ MYSELF’: DISABLING OR ENABLING CONTEXTS

8.1 Introduction

I started **Chapter 7** by referring to Joan who identified a new body and a local bus as the things that could most improve her life. In this, the second of two Chapters addressing the question of how older people experience disablement processes and what meanings they make of those experiences, I explore what I illustrate by the second part of Joan’s comment. That is, that participants experienced disablement not just in the body but in a broader sense, in the way that the body interacted with society. This is the second main category that I identified through inductive analysis.

This means that participants experienced disability as a biopsychosocial phenomenon compatible with international framings of disability discussed in **Chapter 2** (see the International Classification of Functioning, Disability and Health or ICF) and with how disability is understood in critical disability studies (see Hosking 2008; Shakespeare 2014a). Thus, participants experienced disability as an interaction between personal and structural factors and, as Shakespeare (2014a) puts it, they could be disabled by their bodies *and* by society. The findings I present in this Chapter provide evidence to challenge dominant assumptions about older age – in this case, dominant biomedical explanations of disability in older people - consistent with the commitment of critical gerontology to challenge what is taken for granted about ageing and highlighting experiences of disadvantage and difference (see Bernard and Scharf 2007; Phillipson 2013; Grenier 2012).

Having introduced the issue of a ‘disabled’ identity in the literature review for this study (**Chapter 3**) and discussed the issue of identity and ageing in **Chapter 6**, I start here by referring briefly to empirical studies about how a ‘disabled’ identity is understood.

In the main part of this Chapter, I show that there are a range of contextual factors affecting disablement processes in older age, irrespective of the timing of its onset. I discuss four key (and intersecting) ways in which participants perceived themselves as more or less disabled:

1. Social/familial factors,
2. Support/care and Appliances,
3. Physical Environments and Transport, and
4. Socio-cultural meanings in Everyday Interactions.

I show that participants (DwA and AwD) often felt disabled by factors and barriers that also disable people of all ages, such as inaccessible homes and environments and through being marginalised in interactions with others. Experiencing disability with ageing could be perceived as entering a discredited social category – thus, a transition experienced not just at a physical or bodily level but also at a social and cultural level. An inverse process could mean 'normalisation' of aspects of experience for the AwD group. I conclude that biomedical explanations of disability in older age, focusing on bodily experiences alone, omit significant parts of the subjective experience. Neither a societal tendency not to consider older people 'disabled', nor (often) their own non-identification with a disability identity, protects them from disablism.

This Chapter shows how constructions of ageing and of disability, and the social devaluation of each, are intertwined, which means that the issue of disability should be addressed holistically for both disabled people generally and for disabled older people.

8.1.1 Background – Disability-identity and Empirical Studies

I already discussed the issue of disability and identity (in **Chapter 3**). A 'disabled' identity was originally associated with membership of a shared disabled collective, to which Oliver (1996) suggested there were three elements: having an impairment, experiencing externally imposed restrictions, and self-identification. But approaches to identity linked to activism are now challenged because experiences are heterogeneous, because a majority of disabled people do not engage with activism, and because of post-modernist thinking, which makes the construction of a shared political vision more challenging. But as Shakespeare (2014a:13) acknowledges, the contribution that social model thinking made by replacing a deficit approach with a social oppression approach was, and remains, liberating for many disabled people.

Here I wish to refer briefly to empirical studies. Studies with young disabled people suggest that most did not incorporate disability within their identity. Instead, they sought to be part of the mainstream and they normalised the experience of physical limitation (Priestley *et al.* 1999; Watson 2002). This leads Shakespeare (2014a) to conclude that many disabled people emphasise what they have in common with nondisabled people, seeking inclusion and equal status, not separation.

Research suggests that those first experiencing disability in later-life tend *not* to identify with a disability identity, thought to relate to their perception that their functioning is normal for their age (Langlois *et al*.1996; Kelley-Moore *et al.* 2006; World Health Organization and World Bank 2011). They are likely to identify with a medical-model framing of disability (McGrath *et al.* 2017). While the findings I reported in the previous Chapter appear to bear this out, those I present in this Chapter show that limitations at the level of the body are only half the story.

8.2 Social/ Familial Factors

I now present findings from my inductive analysis. In this section I address how participants understood their functioning not as individuals, but in conjunction with the support received from others. They literally experienced more ability to function and participate - less disability - due to the presence of supportive others*.* Conversely, people could experience disability more upon someone’s death, illness or impairment-onset, or in cases of grudging or no support from family or limited support from public services.

Within a lifecourse perspective, the concept of linked lives highlights how people live with others and how changes in others’ lives affect them (Elder, Johnson and Crosnoe 2003). A key finding from this study is that lives are linked in ways that impact on how disability is understood and experienced – on its very ontology. Loss of spouses and other intimates, an experience common to older age (Settersten 2005;2006), makes this aspect of the experience a key feature of later-life disability, and true of both groups – DwA and AwD.

8.2.1. Others Reducing Perception of Disability (or ‘the two of us are one’).

Participants reported positive contributions from family members and sometimes from friends and neighbours. They enjoyed time spent with family members and exchanges of love and affection were very important. But their input also facilitated functioning.

I focus here on what might be called instrumental support that enabled participants to get on with their lives and to continue to live in the community. Spouses, adult-children (especially daughters or daughters-in-law), siblings, nieces/nephews and others helped with tasks like shopping, cooking, housework, transport to events/appointments, and personal care.

Notably, I found that this kind of support could affect how participants understood their own functioning. In other words, their functioning was often understood as part of a relational or social unit rather than as an individual. This was particularly true of spouses. Thus, a participant might describe their functioning as impaired in one dimension (understanding it in an individual or bodily sense) and as not at all impaired in another due to functioning with a spouse – typically in relation to getting out of the home. For example, William (aged 70,DwA) described how his wife helps him function:

> William (DwA): She [wife] puts the clothes on me in the morning anyway and when we’re out together, if I get a steak... I couldn't cut up a steak with one hand so I do get salmon or some meat I can manage myself or she cuts it for me. She does a lot of stuff. She drives me everywhere I want to go. There is a lot of stuff you can't do with one hand.

But when I asked William the functional questions from the Census, he answered a question as to whether he could get outside the home *alone* in terms of how he functioned with his wife as a unit:

> Interviewer: Any difficulty going outside the home alone to shop or visit a doctor's surgery?
> William: I can manage that all right, fairly well. She [wife] brings me like….She brings me wherever I have to go.

Thus, his wife's driving is crucial to how he understands disability. He was clear that this support had to be negotiated at the time of disability onset in his 50s– perhaps partly because their marriage hadn't always been smooth.

Others had similar understandings. For example, Finbar (aged 73,DwA) takes it for granted that his wife will drive him, so he too doesn't consider that he has a problem going out of the house *alone*:

> Finbar (DWA): I just say to the wife, 'we will go here, we will go there.' And that is it.... Nothing really puts me out.

Some seemed to take functioning jointly with their spouses for granted; others were reflexive about it. Desmond (aged 72,AwD) felt that blindness caused him no difficulty. The context for this was an understanding that he and his wife functioned as 'one'. She goes everywhere with him since he retired. Here he describes them walking together:

> Desmond (AwD): But like the two of us are one. Now people say and they often said it to [wife], 'You don't tell him the steps,' and [wife] says, 'Why do I need to tell him? He knows what I'm doing.' It's true……When I'm walking with [wife] I know what she is doing. If she's stepping down I know. The movements of her arm.

Perceptions of oneself not disabled due to the presence of a spouse was associated especially with males in the sample. It is very likely that a factor here is that the caring role is more easily taken for granted in women (Arber and Ginn 1995:26). Male perceptions of relative power in this situation or in society more generally are relevant, I suggest, to these perceptions (see Cancian and Oliker 2000).

Additionally, it may also reflect how there were more married men in the disabled sample than married women (9 males married; 5 females married), in turn reflecting that there are more married men than married women among disabled people aged over 65[59]. (See **Chapter 4)**. This was also discussed more amongst DwA participants, but there were also far

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[59] Amongst disabled people aged 65+ in Ireland: 86,508 married (57% males, 43% females), a rate that increases with age (at age 75+: 39,225 married, 60% males, 40% females) (see **Chapter 2**: calculated from figures in Central Statistics Office online database CD808).

more married people amongst my DwA sample than my AwD sample – only 3 were married amongst the AwD sample.

But some accounts ran contrary to those just given; some participants, including men, understood independence in a more individual way. This appeared to relate to the nature of the relationships they had with spouses, and to how they understood being independent. Colin (aged 88,DwA) did not perceive himself operating as a unit with his wife, instead regretting the loss of independence of not being able to drive:

> Colin (DwA): And I don't like getting my family to drive me, I much prefer to be independent because I carry on from having the car I suppose.

Participants often said they wished not to be a 'burden' on family members and it is perhaps the case that people find it easier to rely on spouses in the way I am suggesting here than on adult children. For example, Phil (aged 74,DwA) relies on adult children to drive him at times, but prefers not to, explaining that he hates to put them out. Thus, it appears that the nature of the relationships and the extent to which the person is conscious of and values operating independently of their spouse or other family members in a given domain of activity is a factor in the *perception* of being more or less disabled.

Of course, this does not take away from the fact that, like William and others, Colin and Phil may in practice experience less disability or fewer barriers to participation, *because* there are family members who can drive them when necessary – in contrast to the experience of others who do not have spouses/adult children, which I will come to below.

Overall, a key point is that participants could partially escape a 'disabled' identity and could experience environments as less disabling due to the way they functioned with others, especially spouses. Alternatively, greater dependence on others could be perceived as one of the consequence of impairment. Thus, both the deeper meaning made of impairment for identity and its practical consequences were linked in participants' accounts of relationships.

8.2.2 Lack of Others, or Impairment of Others, Increasing Disability (or 'We have no children. That is a handicap at our stage')

Conversely, *not* having someone who was willing and able to facilitate functioning was linked to the experience of disablement or greater disability. Those who had lost a spouse or other close person could experience consequent diminution in functioning, as well as loss of the person's company and support. Changes in the health or functioning of an intimate could have the same effect, and precariousness about intimates, as their health/functioning changed, was linked to fears about the maintenance of one's own functioning. Of course, not everyone had a spouse/partner, adult children, or adult children in this country.

Simon (aged 66,AwD), who was visually impaired, described functioning closely with his wife, suggesting they had been 'joined at the hip'. Since she died 'everything has changed': he finds it harder to leave the house, feels 'vulnerable' outside without her and in that respect says he feels much more disabled. Hazel (aged 80,AwD), also visually impaired, lost her husband just over a decade ago. She related her husband's death to its effects on both her day-to-day functioning and to social situations where she feels a 'nuisance' as she must rely on others to: 'help me to the toilet and things like that, if it is a strange house'.

Some, like Julie (aged 80,DwA), were clear that current living arrangements were contingent on others (in her case on her husband's health and survival). Francis (aged 76,DwA) anticipated a move to a nursing home if anything further happens to his wife. He perceived lack of adult children as a 'handicap':

> Francis (DwA): We have no children. That is a handicap at our stage definitely. My wife broke a bone in her back two and a half years ago…….. And she's in pain ever since on and off and it's mostly on now. ……… if we had children now, we'd say, they'd be adults now and at least we'd have someone to drive.

Thus, problems that Francis's wife has with her back means that he is largely confined to home because neither of them can stow his wheelchair in the car, and there are no adult children who might help with this. Similarly, for Peggy (aged 83,AwD) a brother's problems with his hip impacts on her ability to get to Mass, because, she explained: ‘[he] is not able to put me into the car’.

Thus, for some participants, social circles are narrowing as family members become ill, frail or disabled and/or die and this is experienced as disabling. Participants’ accounts demonstrated how those with the smallest family circles or supportive networks could experience disability maximally. The foregoing suggests how community action and public responses are vital, including social aspects of public services aimed at older people. It points up the paradox inherent in the fact that public services aimed at older people place less emphasis on social aspects than do disability services (that is, for adults), as highlighted in the policy review in **Chapter 4**, and the findings reported in **Chapter 6.**

8.2.3 Unsupportive Relationships Increasing the Perception of Disability (or being the one who could never be ‘got rid of’)

The quality of relationships is a factor. While most family relationships discussed were supportive and valued, not all family interactions were positive in general terms or in terms of facilitating functioning. A few participants described grudging support or relationships changing, resulting in less support being available and greater disability being experienced. Participants did not always attribute these issues to disability or impairment but in several cases, they did.

For example, Blanad (aged 60,AwD) attributed her husband’s making a separate life for himself (‘he has chosen to be single’) to her condition having largely confined her to home from age 30. She needs help going into social situations but he won’t help – so she experiences greater confinement. And Teresa (aged 87,AwD), experiencing physical disability from childhood, described a life of grudging support from a brother. Living a confined childhood and adulthood in a rural area, she described him grudgingly dropping her to social events and resentment that she attributed to him experiencing her as the one he would never ‘get rid of’. More recently since his death, Teresa has a sense of hurt and rejection by her sister-in-law who moved out of the home they shared. Teresa attributes this to her sister-in-law not wanting to be her carer when Teresa’s health and functioning deteriorated in her 70s.

This kind of experience tended to be reported in the context of long-term disability and mainly by a small number of people in the AwD group. This may reflect pressure on relationships caused by disability experienced for a long time if family members feel their lives have been negatively affected. This illustrates some of the relational/social disadvantages associated with experiencing disability for a long time, and suggests that the AwD group, or, indeed anyone who experiences impairment for a long time (even if disability onset is later), may require additional support, suggesting that these groups require a particular focus within public policies.

8.3. Support/care and Appliances

I turn now to the second heading: support/care and appliances. Participants with financial resources bought support/care, therapies and appliances to live at home and function. Participants without resources often relied on limited or inflexible public provision of care and experienced more difficulty functioning as a result. But participants also reported supportive public provision. There appeared to be many anomalies and inconsistencies in the provision of support and care to participants – so, for example, some of the AwD group benefitted from high levels of support because they had remained within disability services after age 65, while other AwD participants did not appear to have such levels of support. Also, it was not always clear to me whether home care was provided by disability services or older people's services. While I did initially ask this of some participants, they tended to describe it as from 'the health board' or a specific home-care provider – and did not know if it came from disability or older people's services.

Where they existed, participants valued warm relationships with carers and supportive care that encouraged functioning. Participants understood their functioning in the round, perceiving less disability if resources/appliances and/or public services were available to them (and available in flexible, facilitative ways), on the one hand, and more disability if they lacked them. Again, these perceptions were common to the AwD and DwA groups.

8.3.1 Support and Care Affecting Perceptions of Disability ('No, once the girls are here')

In relation to purchase of care, Hazel's situation (aged 80,AwD) was not typical, but it illustrates how having resources could facilitate functioning and participation, as well as enhancing life. Hazel said that her deceased husband (a business-man) left her well-off. She has a housekeeper who comes every week-day, a home help, a regular gardener and other regular supports. She has a 'family' of migrants who live in her house and alternate the role of keeping her company. It means that she can live independently of her adult children, but with company overnight, is accompanied when she leaves the house, and has help to engage in activities like shopping for clothes or meeting others for lunch. This resembles the role of the Personal Assistant, a key advocacy focus for the disabled people's movement. Thus, Hazel's resources enable her to live securely at home and to engage in enjoyable activities.

Hazel's situation was very different to most participants in terms of ability to purchase support/care. Experiences that were in some respects comparable involved two participants from the AwD group who lived in supported living complexes run by disability services, illustrating how public policies can contribute to minimising the experience of disability.

One was Babs (aged 67,AwD). Born with cerebral palsy, the course of her life has been strongly marked by severity of impairment, and because of it being of a type seen as requiring to be 'safely wall[ed] off' (Davis 1995:7). She spent childhood in hospitals or care settings, adulthood mainly in her family home. In her 20s, the public policy response was to include her in a day centre for older people. When her mother became ill, Babs moved to a nursing home at age 50 with much older residents, but moved out to an independent living apartment at age 60. She continued within disability services after age 65, and she has benefitted from a shift in disability policy towards moving people out of residential settings (see **Chapter 4**).

For her, public policies compensate for lack of individual resources. She enjoys independent but supported living (with carers on call 24/7), and a Personal Assistant who helps her to do things like go swimming. She described her carers as having been supportive and encouraging of her taking on new challenges and making choices, and she is delighted with her current living arrangements:

> Babs (AwD): oh, I LOVE it. And I'm able to go over to [supermarket] on my own and I'm able to go up to the town on my own…… the best thing is you're your own person. There's no one telling you what to do. You are the boss.

At several points she identifies how being 'the boss' is the most positive aspect of life nowadays. As this extract shows, she perceived herself as doing her own shopping. However, she also described a shopping process facilitated by carers – they make a list of what she wants (because her handwriting is unclear), which she needs to show shop-assistants in case she can't reach what she wants from her wheelchair and in case they can't understand her speech.

Babs answered some of the functional questions from the Census – about difficulties going outside alone or washing/showering as 'no difficulty'. Thus, showering presents no difficulty by reference to the fact that there are carers who help. Without them she said she couldn't do it at all, but she didn't think of this as something she couldn't do *because* she has the carers – 'No, once the girls are here'. Thus, the level and nature of support she has fundamentally affects both her sense of self and her functioning.

Others had a different experience. Carmel (age 69,DwA), of a similar age to Babs and also using a wheelchair, experienced disability first at age 65. She was told by a Medical Consultant that she would have to go into a nursing home, characteristic of the custodial care emphasised within aged-care models (Monahan and Wolf 2014). In the event, she rejected that and returned to live alone in her rural home once adaptations were made. But she doesn't, for example, have a Personal Assistant even though she hugely regrets how difficult it is to get out of her home, and 'feels dependent' as a result. She doesn't have care/support on call despite occasions when she falls and needs help. She lacks supports that enable others, like Babs, to live a life experienced as independent and self-directed, but secure.

Several participants referred to home help supports provided by older people’s services being inflexible; a few preferred to do without them for this reason. Tony (aged 83,AwD) (ageing with disability but living in a local-authority ‘senior’ housing complex, not run by disability services) described himself caught between the time allotted for his home help (two hours per week) and that allotted in the communal laundry facility of his housing complex, while also trying to get to attend a day centre - all the same day. His attendance at that day-centre is an important social outlet in a life where opportunities for socialising have diminished – and inflexible service provision risks diminishing participation further.

Thus, it must also be acknowledged that not all of the AwD group lived with the degree of support that Babs had – in fact it was unusual. Peggy (aged 83,AwD) and Teresa (aged 87,AwD), for example, lived alone with support from home helps and from siblings or nephews/nieces. They do not have Personal Assistants and their accounts of levels of support resembled those described by the DwA group like Carmel.

Furthermore, several from both groups, including Carmel (age 69,DwA), who is within older people’s services, reported warm, supportive relationships with home helps and a few instanced home helps being flexible in facilitating them to get on with their lives - one popping in to light a fire outside of her allotted hours, for example, so that the house would be warm when the participant returned from an appointment.

These experiences of disability are shaped by the respective public policy models and practices that operate in disability and older people’s services in Ireland at present, and their different experiences demonstrate various anomalies created by the separate organisation of the two services and how they are implemented. Of relevance is how older people’s services focus on a narrower range of services and are predicated on the availability of family support (National Council on Ageing and Older People and National Disability Authority 2006). This means that some disabled participants were relatively unsupported, especially when they lacked social and financial resources.

8.3.2 Access to Appliances Affecting Perceptions of Disability (or, 'I can walk as fast as anyone else when I have it – almost')

Appliances represent another area affecting perceptions or otherwise of being 'disabled' and where having resources could help with their availability. Without resources, some participants experienced greater disability due to lack of technologies and devices that facilitate functioning. For example, Teresa (aged 87,AwD) spent some time unable to use the toilet/bathroom in her house (having to use a commode) when her functioning worsened requiring her to use a wheelchair that was too wide to fit through her bathroom door. This was remedied when the Coordinator at her local older people's centre got her a smaller, motorised wheelchair.

It is perhaps too obvious to state that appliances could help people to function better, but what is less obvious is that it could affect their sense of identity. For example, Joan (aged 86,DwA) walks using a rollator; she resisted using an aid due to 'vanity', but that changed:

> Joan (DwA): It gradually began to feel quite natural though initially I hated having to use it [rollator]….And it's great, a great help and I can walk as fast as anyone else when I have it – almost.

In pointing out how 'natural' using a rollator feels, and that it means she can go nearly as fast as other people, Joan is both less disabled and perceives that she is like 'anyone else' when she uses it.

Mobility scooters made it possible for several participants to get out alone and a few said that they liked using them. A comment from Janice (aged 66,AwD), shows how this meant that she perceived herself as less disabled as a result. In answering the Census question about difficulty getting out of home *alone*, she said:

> Janice (AwD): Difficulty. Well I use a mobility... Just put 'no' for that.

Thus, being able to get out alone with her mobility scooter, she does not feel disabled in that respect. This points to the complex nature of disability and how participants respond to Census questions reflect not only perceptions at the level of the body, but understandings of functioning in a holistic sense - with no disability reported at times if appliances, relationships or a broad range of contextual issues facilitated functioning and participation.

Furthermore, it points to how initial resistence to using appliances could be followed by acceptance of them, even enjoyment of some because they conferred a sense of functioning like ‘anyone else’. Like bodies and impairment itself, they did not ultimately define them and using them helped participants perceive themselves as not ‘disabled’.

8.4. Physical Environments and Transport

Participants understood their functioning in terms of how their homes and environments facilitated functioning. Accessible transport formed part of making environments and communities accessible. Thus, if homes or environments facilitated functioning, then perceptions of being disabled simply did not arise in certain domains – again underlining how perceptions of disability were broader than the bodily and broader than narrow-biomedical approaches to ageing suggest.

8.4.1 Homes and Home Adaptations Affecting Perceptions of Disability (or ‘it is real awkward at the moment’)

Some participants had made adaptations to homes (paying the cost themselves or getting help from local authorities); others waited for grants to do so, and still others waited for adaptations to be made to local authority housing. Waiting for adaptations meant being more disabled meantime.

Most obviously, a home without stairs or that had a stairlift could be experienced as enabling. Joan (aged 86,DwA) lives in her own home with a downstairs bedroom and bathroom. When I asked her the question from the Census about whether she has any difficulty getting around inside the home, she said ‘no difficulty’ (so was not disabled in terms of the Census in that respect), but she speculated that she would have difficulty if she had to climb stairs.

Being without resources could mean waiting for adaptations. Maggie (aged 78,DwA) only has access to a commode as she lives in a house without a downstairs bathroom. Liz (aged 55,AwD) had a mobility scooter to facilitate leaving the house, but didn’t use it much. She explained that this was because her house lacks a ramp, so she cannot bring the scooter inside.

As she waits for a grant to install a ramp, she describes how inconvenient it is to use the scooter:

> Liz (AwD): It is real awkward at the moment; it is out in the shed and I would have to go out to the shed, open the shed, take the wheelchair out, open the side gate, bring it out, lock up again, come through the house, go back out, go around with the wheelchair. And it is just so awkward. So, if I get this grant, which is a ramp, I can keep the mobility scooter inside the house and just go out on that and I won't have all that messing, it is just straight out.

Thinking about what would make her life better, she described home adaptations:

> Liz (AwD): Well having the scooter inside, and the ramp would be great, and then having a wet room and putting a seat in the shower, that would be so much better.

By contrast, participants with more resources could reduce their experience of disability. Josephine (aged 78,DwA) described how she was unable to hang out clothes on her clothes line, but could afford to use the tumble-dryer instead (‘And to hell with the cost of it’). She described having the resources to have had her house adapted so it enables her to function independently to the maximum extent possible.

So, the accessibility of homes could support functioning and reduce perceptions of disability and having or not having resources directly affected this.

8.4.2 External Physical Environments Affecting Perceptions of Disability (or ‘I’m not allowed to go into town’)

Participants perceived their ability to function as limited by external environments. They identified accessing public transport, using footpaths, toilets and buildings (like shops and restaurants) as barriers. These issues tended to be raised by participants using wheelchairs, rollators or mobility scooters, but hearing-impaired people also experienced environmental barriers (like absence of sub-titles or loop systems). People in the DwA group could emphasise them more – perhaps because experiencing them as barriers was of more recent occurrence in their lives, whereas the AwD group might have become used to working around barriers over a longer period of time. But for participants like Liz amongst the AwD group who lacked financial resources, they could continue to be big issues as, say, public transport had to be negotiated rather than taking taxis:

> Liz (AWD): …..If I wanted to get physio I would have to go to [name of hospital]. When you can't drive, can't' do any of that anymore and trying to figure a way to get buses to these places, it is no joke trying to get places for physio.

Public transport was often perceived as problematic. Paul (aged 69,DwA) no longer uses buses - his wife or son drive him instead. He had tried to use city buses at first after his stroke and after starting to use a rollator. He experiences difficulty with balance and describes how this made using buses difficult as he depended on 'the courtesy of drivers':

> Paul (DwA): Because using transport I'm depending on the courtesy of drivers. And the secret is to get first in the queue…...If I were last there I'd be you know in trouble because the driver would move away before I'd sit down.

Phil (aged 74,DwA) was vehement about environmental barriers. He lives in the city and, following amputation of his legs in his 60s, uses a wheelchair. He experiences difficulty with inaccessible footpaths, buses and was especially frustrated by the DART – the urban train. After disability onset, he used to get the train into the city-centre and spend time with siblings and other family. To use the DART, wheelchair users need a staff-member to put a ramp between the train and the platform and to phone ahead so that there is someone to do the same at the other end. But, as Phil experiences it, his local station tends not to be staffed in recent years, which he attributes to cut-backs and redundancies. He finds this change acutely frustrating and experiences it as being treated as 'second class citizen[s]':

> Phil (DwA): I used to go maybe twice or three times a week. I'd go into town. It was brilliant. ……… Something I'm doing for years I can't do it any more you know. I can't go there. And it's the trains that are at fault, you know. As I've said, the CIE class us as second-class citizens, they do yea. Like they won't put a man there…It's just that hurted me, you know, not to be able to go over and get the DART you know. That hurted me….I'm not allowed to go into town to see my family. That's the way I look at it.

Spending time with his family was a key outlet, now not possible – something that 'hurts' him. He associates it not with disablement in his body, but with changes in political processes that reduce disabled people to ‘second class citizens’. In this way, Phil demonstrates a disability consciousness (fulfilling the three criteria outlined by Oliver 1996, see above) that might be more typically associated with a younger disabled person or activist and might not be expected to be found in someone experiencing disability first in his 60s, given that older people are not generally thought of as ‘disabled’ (and are not treated as such in public policy approaches and in activism).

Amongst those who lived in the countryside, several, including Joan (aged 86,DwA) and Josephine (aged 78,DwA) regretted the lack of a local bus or the inaccessibility of the available busses. Carmel (aged 69,DwA) and Francis (aged 76,DwA), both wheelchair users, felt unable to get out even for a ‘walk’ due to the pot-holes in the road.

June (aged 82,DwA), whose experience of mobility impairment dates from her 70s, uses a mobility scooter and experiences difficulties getting up on footpaths, where drivers park illegally and block the point where there is a dip. She has been to the Garda station to report it and is considering going to the local newspaper. Similarly, Phil (aged 74,DwA) has engaged in lobbying with other people who attend a disability centre.

It may be relevant to their interpretation of these issues and their consequent activism that both Phil and June attend a disability centre that (unusually in an Irish context) admits members experiencing disability onset after age 65. Their cases suggest the possibility of the development of what might be called a disability consciousness and the making of common cause between older disabled people and disabled people generally. Thus, policies and services can reinforce a ‘disabled’ identity (Grenier, Griffin and McGrath 2016) and these findings suggest that this can be the case even if ‘disability’ approaches to policy/services are encountered only later in life.

Finally, for participants with hearing loss, difficulties experienced were often social and within families and social groups. They also experienced barriers in the environment. Seamus (aged 78,DwA), wanted greater awareness of hearing impairment. He has become active in trying to bring this about:

> Seamus (DwA): I want more sub-titling on TV, I want sub-titling on the cinema, I mean the local film club here, and I even went on the committee so that I could get them to show the films with titles. And there was a complete objection to it, believe it or not. People who have good hearing didn't want it, they found it distracting.

Thus, despite his actions, the local film club will not use subtitles.

Looking to the discussion in **Chapter 7** of Bury’s (1988,1991,1997) concepts of *meanings as significance* and *meanings as consequence* of disablement, the two levels can be seen operating simultaneously in these accounts. Experiencing environments as inaccessible was a consequence of impairment, but its significance was interpreted at a deeper level in terms of exclusion and positioning as a ‘second class citizen’, that is, as a member of a discredited social category. I suggest that this (feeling that they were now being excluded from everyday life and interaction) was another way in which the experience of disablement was disruptive of biography and self-concept for the DwA group. Thus, feeling excluded, discredited and discriminated against could form part of the meanings made of the experience and it could also be resisted.

8.4.3 Resources for Transport Affecting Perceptions of Disability (or ‘that makes it so easy’)

As mentioned in **Chapter 7**, participants who used to drive and who had stopped often described it as a big change in their sense of selves as autonomous. Having resources for adapted cars or for taking taxis could help compensate. Helen (aged 68,AwD) described her car as the ‘love of my life’ as it means that ‘life is able to be lived’. By contrast, not being able to afford a modified car was perceived as a key barrier for a few who could neither drive an ordinary car nor afford a modified one.

Unlike Liz (aged55,AwD) quoted above, some people do not have to think about the resources to take taxis, enabling them to get out of the house and participate in a range of activities. When I asked Kathleen (aged 85,DwA) the functioning questions from the Census, specifically, if she had difficulty going outside alone she said:

> Kathleen (DwA): Well, no, I get a taxi. So that…..that makes it so easy.

Her resources for taxis impinge on her experience of disability: as she perceives and experiences it, she has no difficulty leaving the house *alone*. Thus, in this respect she is not ‘disabled’. Disability is something she doesn’t have to reckon with in that context because of her resources. Thus, understandings of how they functioned, and the related issue of whether they perceived themselves as disabled in a particular situation, were related to their resources and ability to drive or take taxis not the (for them) theoretical question of whether they could access public transport, something that could directly disable others.

8.5 Socio-Cultural Meanings in Everyday Interactions

I now come to consider socio-cultural meanings made of impairment, an area where some difference was notable between the two groups. The AwD group had often encountered prejudice early on and some experienced exclusion from roles and stages of adulthood considered ‘normal’ such as attending school, marriage or employment. Some perceived ‘normalisation’ with ageing showing that the meanings made of ageing and the lifecourse construct disability. A different – and inverse – process was experienced by some of the DwA group who perceived rejection in everyday interactions, which they associated with disability onset, showing that the meanings made of disability (as discrediting) construct ageing and the lifecourse. This phenomenon (disability constructing ageing and the lifecourse) is not much discussed in the literature (Kelley-Moore 2010). It may be seen as a surprising finding, given how impairment is often considered a social norm of ageing, and, indeed, it seems at first sight to contradict the findings reported in the previous Chapter that participants often experienced disablement as ‘normal’ or ‘on-time’ for their life-stage.

In this section I look at these two experiences separately, first focusing on the DwA experience and then the AwD experience.

8.5.1 DwA: Becoming ‘other’ (or ‘and now I am the other myself’)

Participants described resisting using mobility and other appliances to begin with, explained as reluctance to be seen as ‘old’ or fear of being ‘left out’ – and perhaps also because it signals or manifests a change that involves limitation and probably finitude. Like the women in Morell’s

(2003:73) study, for participants to be ‘old’ was to be unable to function in some way, and aids required of impaired bodies made one ‘old’.

Josephine, (aged 78,DwA) said she felt very ‘conscious’ of having had to use a stick at age 71, which she explained as an unwelcome occurrence when she was ‘active’ and a ‘young person’. Stephen (aged 88,DwA) said that using a rollator hurts people’s ‘pride’ – ‘they don’t want to admit that they are old’. Seamus (aged 78,DwA) said that he feared being left out of social situations when he started to use hearing aids. Others said they would have previously wondered about disabled people, but not known them – and now they knew that using rollators or wheelchairs, or attending certain centres, meant that others wondered about them. Thus, they were conscious that appliances and aids, or attendance at care-centres, created a gap between how they saw themselves and how others saw them.

Some at least of the initial resistance to using aids was the consciousness that they were crossing a boundary into a discredited or stigmatised category. Joan (aged 86,DwA) characterised using a rollator as becoming ‘other’:

> Joan (DwA): With it [rollator] I am grand, like I just feel…And of course I know that it differentiates me from other people. Because I remember going on a pilgrimage to Lourdes one time and there was one lady with a walker. And I saw her as ‘other’. And now I am the ‘other’ myself.

At another point, she rejects a ‘disability’ identity: talking about why she does not think of herself as ‘disabled’, she said:

> Joan (DwA): I am able to lead a normal, in inverted commas, life, not like if I couldn’t function.

Also, she does not want to be labelled either as ‘disabled’ or ‘old’:

> Joan (DwA): ….don’t define me as..as. Don’t define me by my disability or don’t define me by age. There’s a lot more to me than all of that…I’m still brimming with ideas all the time. Absolutely brimming.

Initial resistence to using appliances suggests that the DwA group was reluctant to cross the boundaries of identity and align with ‘the other’ (Grenier, Griffin and McGrath 2016:14). They not only have to contend with a hostile environment but with their own past conceptions of self (Atchley 2000:148). Joan and others felt that having adapted so as to be able to function meant that they were not ‘disabled’, which they contrariwise associated with being unable to do anything. For example, for Paul (aged 69,DwA), who uses a rollator and a wheelchair following a stroke, suggested that because he has adapted he is not ‘disabled’. Asked if he considered himself ‘disabled’, he said:

> Paul (DwA): No. No. I say I got to learn my capabilities and ways around it. It’s worked. There is no point in staying in the one place pigeon-holing yourself.

This is consistent with studies (cited above) suggesting that those experiencing DwA do not identify with a disabled identity.

These experiences can be best understood when compared with similar experiences amongst the AwD group, in that refusal to be categoriesed as ‘disabled’ was not unique to the DwA group. Participants among the AwD group were more likely to use terms like ‘disability’ and sometimes understood it in a way that was consistent with the social model. For example, April (aged 65,AwD) said: ‘it is society that disables you’. But they could also resist identification with a collective of disabled people. For example, April, who has participanted in disability activism, does not identify with the category ‘disabled’ because she doesn’t want to be treated as if she is different to other people:

> April (AwD): I don’t want people to see me as disabled, because I don’t see me as disabled.

And while Janice (aged 66,AwD) felt that she has made more friendships since having ‘this disablity’ than before (through involvement in disability organisations/centres), she said ‘no’ when asked if she thinks of herself as ‘disabled’: ‘No, not in my head, no’. And Eileen (aged 66,AwD) said, ‘the only thing I want is to be treated normal.’

The point I emphasise is that while the AwD group showed some disability identification, both DwA and AwD groups resist discrediting labels and want to be seen as part of the mainstream. This, Davis (1995:10) and Shakespeare (2014a:99) argue, is the experience of disabled people generally. Consistent with this, both DwA and AwD participants reject the idea of an exclusive ‘normality’, and refuse to be categorised.

8.5.2 DwA: Experiencing and Resisting Exclusion (‘it is not said in so many words, but’)

As already described, the DwA group could find external environments and community groups (like a film-club) inaccessible/inhospitable. They could also perceive rejection and exclusion from communities and even families through everyday interactions. Some participants found that their impairment could embarrass others and they were sometimes depersonalised or excluded as a result. They also resisted this in a way that asserted their value and sense of self-worth.

For example, Francis (aged 76,DwA) explained that friends/relatives were ‘embarrased’ when he visited using a rollator:

> Francis (DwA): But they always would get embarrassed that I’d come in with the rollator…..They were embarrassed for me, I suppose. And they’d say, ‘I’ll put this here near a door and you can get it on the way out.’ And in the first place I couldn’t get to the rollator on the way out. I’d be sitting there stranded until I’d either have to ask them to get the rollator for me or stay longer.

By removing the ‘marker’ of his disability – his rollator – they were disabling him. He experienced something similar with his wife, whose reaction affected his attendance at Mass. Talking about his wife not liking him to come to Mass using his rollator, he said:

> Francis: …. I suppose she thought it was a slight on her. Even though I didn’t think it would. But that’s what she’d think. …….But she never said it to me - ‘Don’t go parading up the chapel with the, a rollator.’
> Interviewer: She never said it?
> Francis: No. She wouldn’t. She never says it to me.
> Interviewer: And you felt it at the same time?
> Francis: I suppose I did. But not to an awful extent.

Francis is conscious of his wife’s embarrassment at his rollator, or marker of disability, *and* he minimises its impact on him – he says it didn’t bother him ‘to an awful extent,’ even though it meant not attending Mass. At another point he said: ‘But there are things that I’d like to do but at seventysix, you might as well start slowing down'. As Holstein and Gubrium (2000) remind us, people use perceived lifecourse norms – such as images of events being 'on-time' or 'off-time' – to constrain behaviour. It is possible that Francis is here invoking a 'decline ideology' (Gullette 2004) in part at least to help deal with the suffering or prejudice associated with the experience of disability. This echoes Luborsky's (1994:237) argument that being in the world with disabilities is an experience 'permeated by impulses to withdraw or sequester oneself from others'. Thus, accepting 'decline' and associating that with withdrawal, participants may be adopting strategies to deal with stigma, amongst which Goffman (1963) identified limiting social interactions and hiding impairments (on the part of disabled people generally)[60].

Francis experienced sudden onset of disability at a relatively young age (58) and these reactions might be seen in that context. However, Francis feels that his wife continues to feel embarrassment about his use of an aid – nowadays a wheelchair - even though almost 20 years have passed since he first needed to use a rollator and given that he and his wife are now past their mid-70s.

Joan (aged 86,DwA), who experienced gradual onset of mobility issues in recent years, described an incident where a family member reacted to a walking-stick, a 'marker' of disability. Joan brought a stick to her son's house intending to lend it temporarily to her daughter-in-law who was recovering from an operation. Joan's granddaughter reacted:

> Joan (DwA): [She] immediately went into a cannuption of 'Oh no, no, no no no'. And I was *shocked.* Because at that stage I'd got quite used, t'was just a part of me but *a part.* It [walking-stick] wasn't

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[60] Goffman (1963:3) defines stigma as a sign or mark that designates the possessor as spoiled' and less valued; it is 'deeply discrediting' and reduces the bearer 'from a whole and usual person to a tainted, discounted one.' When I talk about stigma, I take debates within disability studies into account, such as Scrambler's (2009) discussion of the importance of the context of social structures such as class, gender and ethnicity and emphasising the importance of social processes (not just individual ones) in explaining the concept. Link and Phelan (2001:367) suggest that through processes of labelling, stereotyping, separation, status loss, and discrimination, stigma results in creating an 'us and them' mentality that results in 'othering' and exclusion of one group of people by another more powerful group.

> *me.* But she saw it as *me*. I was deeply hurt and I was enraged more than anything else.
> Interviewer: What do you think she meant or how did you experience it?
> Joan: Like that *I* was *other*, *but* her mother…[pauses]

Joan experienced her granddaughter's reaction as rejection and depersonalisation – as an indication that Joan has been placed in a category below the 'normal':

> Joan (DwA): It was…was seeing me as just an old woman with a stick.

Talking about the past ten years, Joan said that one of the biggest changes was her consciousness of others' perceptions of her 'as an old disabled person':

> Joan (DwA): Well I suppose others' perception of me…as an old disabled person. I feel conscious, very conscious of that.
> Interviewer: That that's how you're perceived now?
> Joan: Yea. It doesn't bother me somehow. Well at this stage I've got used to it...I've grown into it like [laughs]. So what like if that's the way.

Thus, it is not bodily impairment that Joan identifies as the biggest change of recent years – even though her body is painful and disabling - but how others consign her to a discredited category. Thinking of Bury's (1982;1997) notion of biographical disruption, this is another way in which the experience of disablement is disruptive of biography and self-concept even when experienced gradually in older age.

But Joan doesn't accept that identity – it is not at the centre of her self-definition. And she has learned to cope, part of which is not to be too bothered by others' attitudes. What she describes here is similar to Wendell's (1996:26) description of adjusting to a disabled identity involving accepting the reality (though not the justice) of stigma, and to Charmaz's (1991:660) argument that chronically ill people can move beyond loss and transcend stigmatising negative labels, defining themselves as more than their bodies.

I give one further example here which shows that exclusion could be perceived even within a community of older people. Carmel (aged 69,DwA), using a wheelchair for the first time in her 60s, is excluded from outings by a local group of older people *because* she is disabled. There is an accessible bus, so she attributes it to an unspoken prejudice on the part of those who run/volunteer the organisation:

> Carmel (DwA): ….. but there are times that I certainly feel disabled, like when you can't go on the bus when there is a group going to a shopping centre and you can't go. You can't go on an outing to the seaside…... That does make me feel bad…… It is not a problem with the bus, it is only a problem with the organisers. They think I am disabled. I don't have any legs so how can you go shopping like everybody else? It is not said in so many words but there is no other reason why I can't go.

Carmel feels 'bad' as a result and she has challenged the situation pointing out that she can wheel herself. She identifies how she 'feels disabled' on these occasions – in other words, being disabled is not so much a fixed condition of impairment but something she experiences *when she is excluded*. Even if the impaired body is not central to her concept of identity, it affects others' perceptions of her, resulting in exclusion from a group of age peers. Some studies suggest that the AwD group can experience barriers to participation in places targeting seniors (Raymond and Grenier 2013; Raymond, Grenier and Hanley 2014), but this example illustrates that this exclusion can apply to the DwA group as well.

Crucially, these findings suggest how the withdrawal that is associated with the so-called 'fourth-age' can in fact be constructed through everyday interactions and inhospitable/inaccessible environments. Thus, they show how distinctions (third-age/fourth-age) accepted in conventional approaches to ageing and the lifecourse can be achieved and circumstantially shaped – and are shaped especially by meanings made of impairment.

Furthermore, participants' responses to others' attitudes involved hurt, anger or resistence (voiced or unvoiced), resembling the resistance of disability activists generally, which, Watson (2003) shows, can also be indirect or unspoken. Participants often resisted negative categorisation and continued to take opportunities for continued engagement in whatever activities were available/accessible and to communicate a sense of self-worth and that their lives have value. For example, Francis explained that he feels 'case-hardened,' which means that people must take him as he is:

> Francis (DwA): They can take me as I am or forget about me…..Yes. Here I am. That’s it.

The exclusion or discrediting experienced relates to markers of disability – sticks, rollators and wheelchairs. It is clear that these issues relate to disability *not* age – particularly obvious in the case of Carmel who experiences exclusion within an older person’s group where other members are older than she. In short, despite not being considered ‘disabled’ in general perception, in their own accounts, and in public policies, participants suffer the negative aspects of disablism[61].

8.5.3 AwD: ‘Normalisation’ (or ‘maybe it was more of a problem when I was younger’)

Participants in the AwD group could describe an inverse process. Thus, they sometimes perceived that with ageing lives had ‘normalised’ in some respects, as meanings they and others made of ageing and the lifecourse constructed disability as less stigmatising at their life-stage. Still others experienced not just ‘normalisation’ but a positive, new sense of engagement with ageing – and this could be experienced over a period of time in tandem with ongoing or worsening bodily challenges and often by people who had lived lives they perceived as very confining.

While as a group, they were heterogeneous in a range of personal/biographical and other ways, their perspectives were often informed by lifecourse trajectories strongly marked by how disability was constructed and ‘managed’ in society (Irwin 2001). Some referred to instances of othering throughout their lives - being ignored and talked over or of intrusive questions from non-disabled people. ‘Normalisation’ appeared to occur because of the link made between being older and being impaired, as impaired bodies could be experienced as less stigmatising when compared to others (Priestley 2006; Jönson and Larsson 2009), as could the need for care/support. So, for example, Eileen (aged 66,AwD) who has had professional carers throughout life, seemed to experience this as more ‘normal’ with ageing (‘it’s time I should be looked after’).

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[61] Disablism: discriminatory, oppressive or exclusionary behaviour arising from the belief that disabled people are inferior to others (Miller *et al*. 2004:9), or ‘the outcome of the withholding of social and cultural recognition’ (Watson 2003:50).

Blanad (aged 61,AwD) enjoys activities at an active older people's centre and says: 'I love being part of the older generation,' which, given her relatively young age, may be surprising. But for her it seems to be associated with having re-entered the standardised life course understood as having activities to engage in and having a community to which she can belong following years of confinement, being different to her peers, and, as she said, having had no 'identity' outside of her diagnosis of Parkinson's disease. Thus, public services and/or inclusive community organisations played a key role in positive perceptions - involving possibilities for a sense of belonging and more choices of activities.

Helen (aged 68,AwD) discussed the experience of 'normalising' explicitly. Her disability is based on appearance, due to curvature of the spine, which created health challenges and further impairment, especially from her early 40s, including pain and having to use a machine for oxygen at night. More recently she experiences worsening pain and needs to carry around an oxygen tank at all times. In one respect she felt that life had normalised because people had always stared at her visible impairment, but that is of less concern now:

> Helen (AwD): Well I am at the stage in my life I suppose…. when you have scoliosis, and mine is quite visible, you get used to people looking at it, and I am at the stage where I am not too worried about the fact that, well I have to wear it [oxygen tank], but I am worried about the fact that it is such a nuisance for me to carry it around……. I suppose I got used to that, maybe it was more of a problem when I was younger and going to dances and things because you can see where you would run into problems there. But now it is not such an issue. That is the beauty in some ways of getting old, some things are less of an issue and other things become an issue. But no, it doesn't bother me, now I don't care less, it is more your problem than mine.

Helen articulates both of the hypotheses outlined in **Chapter 3** about how people age with disability: there is both a 'double difference' *and* an element of 'normalisation'. She associates greater difficulty breathing and a painful body perceived as 'deteriorating' with ageing (at a relatively young chronological age), making life increasingly difficult. But her perceived impairment, because it was visible, was more of a problem when she was 'going to dances' – so the exclusion that it caused as a young person socialising is no longer an issue. Thus, ageing and the lifecourse constructs the meaning of disability by making her visible impairment less visible, or less noteworthy in the eyes of others – the linking of ageing and impairment helps Helen to stand out less, to resist others' judgements more than when she was younger and to assert her own sense of self-worth and of living a life of value.

Thus, there can be both disruption and 'normalisation'. In **Chapter 7**, I argued that Helen's experience had been of a series of disruptive events across the lifespan that continue now, and that acute fear of greater dependency that she now experiences was consistent with the notion of biographical disruption, especially as Larsson and Jeppsson-Grassman (2012) understand the concept - that it does not have to be a single or wholly unanticipated event. In Helen's case, a sense of 'normalisation' improves aspects of life, but it does not obliterate the disruptive aspects of further complications and fear of greater dependency.

For others, ageing brought not just 'normalisation' but an expansion of activities/participation, especially notable amongst those who experienced earlier periods of particular confinement or lack of autonomy. A local disability or older persons' centre could play a big role in life nowadays especially if there had previously been few opportunities to get out of home.

This was most marked amongst participants, such as Babs, discussed above. who had lived in residential care settings in mid-life but had moved to supported-living complexes run by disability services later. But others also experienced it. For example, Teresa (aged 87,AwD) said of living in the family home throughout adulthood: 'I might only get out once a year'. She emphasised positive experiences of recent years, despite disimprovements in functioning (including moving from using crutches to a wheelchair, gradual loss of her sight, falls and fractures, and illnesses including pneumonia). She too seems to experience disruption *and* 'normalisation'.

Thus, within the past decade she has experienced multiple bodily challenges involving stays in hospital and nursing homes. At one point she feared that she was on a trajectory going ever downhill towards greater dependency: 'the idea of going into an old people's home, that is what was getting me down'. She quoted a nephew saying to her, 'What is going to happen now every time you come home and find yourself on your own - you are going to get sick' – and how she resisted this, saying to herself, 'No, I am not, I won't have that'. During this period, the sister-in-law with whom she lived following her brother's death moved out (because she did not want to be Teresa's carer, as Teresa perceived it) – and Teresa was hurt and exercised about this, saying about living on her own for the first time ever, 'it can be very lonely at times'. But at the same time, now, living on her own since her late 70s (with support from public services), she conveys pride in being independent: 'I am on my own. And I am independent'. And a key change came in recent decades when she started attending the local older people's centre and became part of her community for the first time, which has 'opened up a new life':

> Teresa (AwD): So that was grand. It really opened a new life for me and I went on holidays with them and everything.

All of this points to an experience of repeated cycles of adaptation. Thus, there is both biographical disruption caused by bodily challenges leading to fears of dependency and negative impacts on relationships *and* simultaneously a sense of entering the standardised lifecourse and 'normalisation' through perceptions of being both 'independent' and part of her community for the first time in recent decades. In taking up opportunities to connect more with groups in their communities and to make their own decisions, these participants are engaging in remaking their lives where they can.

8.6 Discussion

In this Chapter, I discussed how participants experienced disablement in terms of interactions with disabling contexts, having shown in the previous Chapter how they (additionally) perceived that their bodies disabled them. Combined, the two Chapters show that participants experienced disability in an interactional (or biopsychosocial) sense where disability arises from the interaction of individual conditions with contextual factors. This definiton orginates in medical sociology, is consistent with supra-national classification (the WHO's ICF and the UN Convention onf the Rights of Persons with Disabilities), and with approaches to defining disability within post-social model or critical disability studies (see Hosking 2008; Shakespeare 2014a and **Chapter 2**). Participants were dealing with existential challenges that were the inevitable results of senescence and finitude *and* contingent challenges that are social in origin and can be alleviated (Settersten and Trauten 2009).

I used as headings four factors that I identified in the data as constitutive of the experience of disability (in addition to bodies): (1) social/ familial factors, (2) support/care and appliances, (3) physical environments, and (4) socio-cultural meanings in everyday interactions. These factors were interlinked and influenced experiences of disability and often self-identities. They could be experienced as barriers or as facilitative and both having access to resources or otherwise facilitative public services could be relevant to how they were experienced.

I started by looking at how experiences of disability occured within lives linked (or, increasingly, not linked) to others. Participants perceived themselves as not 'disabled' in some domains (like getting out of the house), and experienced fewer limitations if a spouse or other family supported their functioning and participation. There was a gender aspect to this, as some men could take support of wives for granted and perceive themselves as not disabled in some respects if their wives facilitated their functioning. Alternatively, loss of, or absence of, intimates, or unsupportive relationships, contributed to greater perceptions and experiences of disability. Thus, the experience of losses amongst intimates shapes disability in older age. The likelihood of this may differ depending on socioeconomic contexts (Baars 2010), and it certainly does so depending on gender (as women are more likely to be widowed and disabled in older age than men - see **Chapter 4**). Additional strains on relationships that participants from the AwD group, especially, linked to long-term disability, suggests the need for a particular policy focus on anyone experiencing disability over a long period of time.

Coming from a certain class or having access to financial resources, or alternatively public services (that facilitated engagement, and/or provided warm relationships and security) could also reduce perceptions of disability. This was particularly notable for a small number of participants, amongst the AwD group, living in supported-living complexes run by disability services who enjoy services that take adulthood as the reference category (rather than older age). Others too from the AwD group who had lived lives marked by marginalisation perceived lives that were more connected now, associated especially with finding new ways to participate in communities, sometimes with groups of older people. This was premised on actions by public bodies/communities (that is, accessible, attractive, inclusive centres that provide transport).

These findings are consistent with research on how less socially integrated elders perceive greater disability, independent of functional status, and how those with least social support face ‘the most naked forms of precariousness’ (Kelley-Moore *et al.* 2006; Hagestad and Settersten 2017:142). Given that increased likelihood of bereavement and reduced social networks distinguishes older people from others (Settersten 2005;2006; Baars 2010), this is a systemic issue that should inform collective societal and community responses. One implication is that disabled older people should be encompassed within active ageing approaches as their community participation cannot be left entirely to the families, friends and neighbours (as argued by Litwin and Levinson 2017:17).

Participants from the DwA group tended to stress environmental barriers – like undipped footpaths, partially accessible homes and public transport - *more* than the AwD group, presumably as they had encountered them as barriers more recently. Public provision of, or alternatively, having resources for housing adaptations, appliances, and taxis could reduce experiences of disability for both groups. In certain domains participants were not ‘disabled’ either in terms of their identities or in practical terms, while others experienced difficulty (in having to use public transport or negotiate inaccessible houses). Members of the AwD group who had least access to resources continued to stress difficulties with home/community environments. Accounts of suffering from being excluded from a community group (like a film-club) or treated like a ‘second-class citizen’ in public transport showed how disability experienced for the first time in older age could be experienced as oppression in a classical social model sense (see UPIAS and Disability Alliance 1976; Finklestein 1980). It also shows how threats to one’s sense of self were not solely perceived as a result of bodily changes (even if that was the basis for them). And it confirms the importance of practical measures in various environments that help people to experience less disability and continue to engage (see contributions from environmental gerontology, Wahl, Iwarsson and Oswald 2012; Hallgrimsdottir and Stahl 2016).

In **Chapter 7**, I showed how participants often perceived their stage of life as ‘on time’ to experience impairment and thus the social construction of age and the lifecourse affected the meanings they made of disability**.** This Chapter’s findings suggest that the link made between being older and being disabled could benefit the AwD group by ‘normalising’ the experience, as they perceived that their lives began to look more like the lives of other older people in some respects. Ageing could make a visible impairment less noteworthy in the eyes of others or make someone feel less conscious of impairment. This is consistent with empirical studies reviewed in **Chapter 3** (see Jeppsson-Grassman *et al.* 2012; Jeppsson-Grassman 2013:31; Bishop and Hobson 2015). As I argued in **Chapter 7**, for this group there could be biographical disruption from ongoing bodily challenges that caused curtailment of activities, fears of greater dependency and negative impacts on relationships (see Bury 1982; Larsson and Jeppsson-Grassman 2012). However, at the same time they could experience an element of ‘normalisaton’ in aspects of life, because their appearance or need for support was less noteworthy or they achieved greater community involvement, sometimes with groups of older people. In choosing to engage and in this way where they could, they were seeking, I suggest, to create lives of greater meaning and value and processes of ‘normalisation’ could help with this.

Another framing - how social constructions of disability frame the meaning and experience of ageing and the lifecourse – has received limited attention in the literature (Kelley-Moore 2010). I showed how the social construction of disability (as discredited or not conforming to what is considered ‘normal’) could affect the DwA experience. Participants perceived that appliances associated with impairment marked them as ‘old’, as to be ‘old’ was to be unable to function in some way. They could also perceive exclusion and discrediting resulting from starting to use markers of disability

– hearing aids, sticks, rollators and wheelchairs. As Priesley (2003b:58) suggests, the appearance and trappings of the impaired body are highly relevant in older age. By taking a constructionist approach to the lifecourse these findings suggest how the so-called ‘fourth age’ (or the extent to which it is associated withdrawal and stepping back) can be interpretively achieved in societies through environmental barriers and in every-day interactions.

Thus, disablement, first experienced in later-life, could involve transition not just at a physical or bodily level but also at a social and cultural level. For example, exclusion from public transport could lead to feeling classed as a ‘second-class’ citizen. Others’ negative perceptions of one as an ‘old, disabled person’ associated with use of aids and appliances could be perceived as a significant change. This is consistent with the findings of Sanders, Donovan and Dieppe (2002) that older participants experiencing osteoarthritis could experience stigma related to using aids or wheelchairs. These experiences contributed to participants’ perceptions of biographical disruption (or threats to taken-for-granted assumptions and self-concept). I suggest that for participants in this study these perceptions could also contribute to a sense that life made less sense and to the need to remake aspects of life (I discuss this especially in **Chapter 9**). My findings show that this happened to people with different impairment types and different conditions, including people who had experienced both sudden and gradual onset of impairment. They could also resist others’ discrediting attitudes and assert instead a sense self-worth and that their lives had value.

These are, I suggest, somewhat surprising findings, given that in the sociology of illness literature on biographical disruption, ‘the debilitating effect of stigma’ is often associated with the symbolic meaning made of particular conditions which people fear due to the emphasis in modern cultures on bodily control (such as epilepsy, colitis, or cancer of the bowel) (see Schneider and Conrad 1983; MacDonald 1988, both cited in Bury 1997:125; Kelly 1992)[62]. Because my study is with older people with

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[62] Stigma is also explored in other literatures such as rehabilitation, when it tends to be approached from the perspective of a particular illness such as stroke (see White *et al*. 2012; Royal College of Surgeons in Ireland 2014). There is also scholarship in gerontology on the stigmatising aspects of dementia.

different impairment types, my findings point to a more general experience than research limited to one diagnostic type suggests. Thus, I suggest that participants' experiences of stigma or feeling discredited by others contributes to a sense of biographical disruption, and that this is somewhat paradoxical given that it happens at a time when impairment is considered a social norm. It is also likely to be a widespread experience.

To summarise this discussion from the previous Chapter and this one, I suggest that for disabled elders a range of factors contribute to the experience of biographical disruption. These include a heightened sense of finitude, uncertainty about day to day life and the future, not being able to control things, possible fundamental change in social lives and greater dependence, loss of activities and participation outlets, and loss of related social identities and roles *and* feeling excluded or marginalised by inaccessible environments and discrediting attitudes of others (the last particularly reported by the DwA group). I suggest that for those who experienced sudden onset of disability in older age, the experience was often consistent with Bury's (1982) original concept. Over time sudden onset may, of course, be followed by a series of further changes leading to further disruptive episodes and requiring ongoing adaptation. For many participants (DwA and AwD groups), the experience was consistent with Larsson and Jeppsson-Grassman's (2012) expanded version of the concept (that is, not a single event in a life untouched by health challenges). They developed this version out of research with people ageing with chronic illness or impairment (that is, AwD group). I suggest that, as well as worsening impairment amongst the AwD group, their version of biographical disruption can apply to the DwA group - those experiencing gradual onset and those experiencing further challenges that can follow sudden onset. In all cases, disablement experiences can be significantly disruptive of the sense of self.

Looking at the exclusion and discrediting that the DwA group experienced through a critical disability studies lens is instructive. What participants often described, though no one used the term, was disablism. Yet marginalisation or exclusion from the mainstream of social interaction that is the experience of disabled people generally (Watson 2003: 40), could also apply to the DwA group. These participants experienced being ignored or depersonalised, had agency denied, or experienced embarrassment or fear on the part of non-disabled people, just as (younger) disabled people often do (see Watson 2003) – and they linked it not to their age but to their use of aids such as rollators and wheelchairs. Thus, a societal tendency not to consider older people 'disabled' does not protect them from disablism, which I suggest is a more widely experienced phenomenon than may be generally appreciated.

Related to this, I suggest that there may be a link between accepting a 'decline ideology' in older age (Gullette 2004) and the experience of disablism. Some behaviours amongst the DwA group were compatible with ways that disabled people generally withdraw or avoid social activities/roles to attempt to avoid stigma and preserve a sense of self as a whole person (Goffman 1963; Luborsky 1994:246; Morris 1991;2001:6,10). Thus, identifying with 'decline' and associating their stage of life with it being time to 'slow down' or withdraw, may be used to buffer participants' self-concept when faced with disablism. Thus, I suggest that disablist reactions to impairment are a key component in the very construction of the 'fourth age' as a time of withdrawal and stepping back.

Not generally using the term 'disability' and often stressing that what they experienced was 'normal' for their age, the DwA group predominantly did not want to identify with a potentially stigmatising label. These participants nonetheless communicated resistence to prejudice or disablism, which was similar to voices represented in disability studies literature (see Morris 1991:17; Watson 2003). They could therefore experience the prejudice and exclusion of disablism without the sense of support or solidarity from identifying or connecting with other disabled people. For example, Wendell (1996:27) suggests that connecting with other disabled people helped her to feel no longer 'struggling alone'.

Furthermore, a few from the DwA group *did* engage in activism to address accessibility issues and exhibited what is considered a disability identity (see Oliver 1996, quoted above). Involvement with a disability organisation, presumably with a disability consciousness, was a likely factor in this orientation in some cases. This suggests that non-identification with a 'disability' identity amongst the DwA group in general results in part from the schism between policy frameworks and activism on disability and ageing (with their different underlying models). This is consistent with how public policies in the fields of both ageing and disability can help shape membership categories that affect identity (as I argued in the Introduction to this study and in **Chapter 6**) and with the reminder from Jenkins (2008:43) that both asserting and resisting collective identification is ‘definitively political’.

But the picture is complex, as identifying with a disability collective was not a given amongst the AwD group. More likely to use the terms ‘disability’ or ‘disabled’ and to understand disability in a social or biopsychosocial sense, they had analytical or political approaches informed by disability activism and they sometimes had collective experiences over their lifetimes with other disabled people that they valued. Simultaneously, they could be reluctant to identify with disability as a collective. They perceive their experiences as ‘normal’ and are also reluctant to be thought of primarily in terms of bodies or impairments.

Finally, I suggest that why both being ‘old’ and ‘disabled’ is perceived as discredited is bound up with perceptions of vulnerability and fears about not being fully human, or what Kristeva (1982:149) calls the ‘contamination of life by death’. This points to the need to rethink normalcy, as critical disability scholars argue (see Davis 2013b:12), as denial of the realities of vulnerability in society at large can damage disabled people (of all ages) (Baars 2010:115). I suggest that the degree to which the constructions of ageing and disability are intertwined confirms the assertion of Riddell and Watson (2003:16), quoted in the Introduction to this study, that ‘there is no point in developing positive images of disabled people if older people continue to be socially devalued’. It also confirms its opposite – that there is no point in developing positive images of older people if disabled people continue to be socially devalued. This means that the social devaluation of disabled people and older people needs to be addressed holistically across the life span. As I suggested in the Introduction to this study, this requires a realistic engagement across disciplines with the nature of humanity, including its limitations, something requiring a critical response to orthodoxies in both disability studies and social gerontology.

8.7. Conclusions and Implications

In this Chapter I showed that a range of contextual factors contribute to the experience of disabilty in older age irrespective of the timing of its onset. Combined, the findings I discuss here and the previous Chapter demonstrate (through an inductive process) that participants experienced disability in an interactional (or biopsychosocial) sense arising from the interaction of individual conditions with contextual factors. I conclude that biomedical explanations of disability in older age, focusing on bodily experiences alone, omit significant parts of the subjective experience – parts that are amenable to change.

Participants (DwA and AwD groups) often felt disabled by social factors, environments, systems and attitudes that disable and/or marginalise all disabled people. Loss of intimates was a characteristic feature that increased perceptions of disability, and those with least resources (social and financial) could experience disability maximally. Supports offered by public services could reduce perceptions of disability, and some of the AwD group particularly valued how their services promoted self-direction and participation. They also reduced perceptions of disability.

A key finding of this study was that meanings made of disability were bound up in the social construction of ageing and the lifecourse, and meanings made of ageing and the lifecourse were bound up with the social construction of disability. This meant that, for the AwD group, ageing could be ‘normalising’ in some respects and they could take the opportunity to reshape their lives through more engagement in their communities (if facilitated by public/community action to do so). On the other hand, for the DwA group, to experience impairment (especially starting to use aids/appliances) could mean encountering prejudice and exclusion. I suggest that disabling environments and disablist reactions to impairment are a key component in the construction of the ‘fourth age’ as a time of withdrawal and stepping back. Non-identification with a disabled identity does not protect disabled elders from disablism. Neither does a societal tendency not to consider older people ‘disabled.’

Thus, for the DwA group, feeling excluded or marginalised by others from everyday life and interaction, and consequently feeling they had entered a discredited category, was another way in which the experience was disruptive of biography and self-concept. They often resisted this or tried to work around it and in so doing were trying, I suggest, to remake their lives so that they could perceive them as meaningful.

I conclude that the extent to which constructions of ageing and of disability, and the social devaluation of each, are intertwined means that this needs to be addressed across the life span for both disabled people generally and for disabled older people (irrespective of timing of disability onset).

Amongst the key research and policy implications are that more understanding of social constructions of disability in older age and of the associated transitions, not just its biomedical aspects, are needed. Research that crosses disciplinary boundaries could help with this. An implication for public policy is that communal responses, not just individual level responses, are necessary to respond to disability in older age. Furthermore, public policies need to have a focus on those who lack social and material resources.

Concluding Remarks

I discussed experiences of disablement and meanings made of disablement processes in these two Chapters (**7** and **8**). This involves being disabled by bodies *and* by society and (often) resisting the imposition of discrediting identities.

In the next Chapter, I address the second research question - how do disabled older people respond to processes of disablement. I suggest that they do so by attempting to reorient towards meaning in their lives following loss.

CHAPTER 9: ‘I AM CONFINED MORE OR LESS TO THE HOUSE UNLESS I DO SOMETHING ABOUT IT’: RESPONDING TO CHALLENGES.

9.1 Introduction

In the previous two Chapters, I addressed processes of disablement experienced in older age. In this Chapter I address another research question - how do disabled older people respond to the challenges involved? I present findings on the third main-category that I identified through my inductive analysis – responding to challenges. That participants did respond, is summed up in what one said:

> ‘I am confined more or less to the house unless I do something about it’.

I have already discussed the ongoing uncertainty that participants lived with and how activities and roles ceased to be available or accessible, and the ways in which they could feel excluded or marginalised from opportunities for engagement and confined to home by environmental barriers to participation. I showed that the perceived consequences were significant in a range of ways and argued that they amounted to disruption of the taken-for-granted, involving a potentially damaging loss of control and altered social relationships, consistent with the medical sociology concept of biographical disruption (Bury 1982;1997:124; Larsson and Jeppsson-Grassman 2012). I argued that in their efforts to cope with disablement processes they were trying to maintain a sense of value and meaning in life.

This Chapter reports on how loss of intimates was intertwined with disablement processes and focuses on participants’ responses to the combined challenges. I show that the ways they responded to the twin challenges of disablement (or worsening disability) and loss of intimates amounts to engagement in a dynamic process of trying to maintain or restore a sense of meaning in life. Combined, this and the previous two Chapters illuminate the overarching conceptual category of this study – how participants were seeking to remake lives that make sense.

Before reporting findings, I return to the issue of meaning in older age, raised in **Chapter 3**, and I address what I understand by ‘meaning in life’. I then show how unprecedented losses amount to threats to perceptions of life as meaningful for older disabled people - meaning-making becomes at once more important and more challenging. In the main part of this Chapter, I show how faced with this, participants engaged in processes no less challenging than trying to restore order following disruption. The Chapter shows how they do this by investing everyday activities with new meaning and through efforts to maintain participation opportunities, connections and opportunities to contribute. I go on to show how, for some, community organising and public responses help to address losses of activities and people. I argue that all of this amounts to attempts to live meaningful lives expressed through efforts to have a sense of purpose or self-fulfilment, self-worth, moral-worth, self-efficacy and connection with others.

Participants continue to identify with goals of self-development, activity and social connectedness more typically associated with the third age. This process is essentially a meaning-making one as there is an intrinsic connection between self-realisation and a search for meaning. They experience limitation and vulnerability simultaneously with resourcefulness, creativity and determination.

9.1.1 Theoretical Context: Meaning Generally

Taking an inductive, grounded theory approach, this study did not set out to explore the issue of meaning in life, but my analysis suggested that this was a key concern for participants. I interpreted the data to suggest that, in a fundamental way, participants were engaged in a process of trying to remake sense of their lives. I have discussed how participants experienced threats to their sense of a valued self, and sometimes anticipated a future unwelcome self. This can also be seen as part of a process in which one’s sense of life as meaningful was threatened and one has to respond – threats to identity can also be about wanting to have a sense that life makes sense (Bury 1991; Baumeister 1991:77). As Bury (1991:461) suggests, attempts to learn to cope with chronic illness are about trying to maintain a sense of value and meaning in life. I take up here the discussion I started in **Chapter 3**, where I introduced scholarship on meaning and ageing, which occurs especially within moral economy or cultural approaches to ageing.

First, what do I mean by ‘meaning’? ‘Meaning’ is a way to make sense of one’s existence (Stillman *et al.* 2009). Scholars distinguish between meaning-making processes related to finding meaning *in* life, on the one hand, and concern with the meaning *of* life, the latter seen in a metaphysical sense (Laceulle and Bars 2014:35; Edmondson 2015; Holstein 2015; Laceulle 2016)[63]. My concern is with the first – meaning *in* life – or how people form a sense of meaning in their lives with the means that society and culture offer (Baumeister 1991:9).

Perceiving that one is living a meaningful life is associated with a range of positive outcomes like satisfaction with life, happiness, even physical health and wellbeing (Stillman *et al.* 2009) or living longer (Krause 2009). Indeed, happiness is considered impossible if one feels that life is meaningless (Baumeister 1991; Derkx 2013).

Meaningful orientations are context-specific and related to cultural meanings (Baars and Phillipson 2014). Despite the unstable, socially defined nature of the self in late modernity, there is still ‘a deep-rooted need in people for a sense of coherence and integration of one’s identity’ (Laceulle 2014:103), and late modern striving towards a life of one's own indicates the continuing appeal of self-realisation as a moral ideal (Laceulle and Baars 2014:40). In fact, individualisation processes have made meaningfulness of life extremely dependent on the development of a valuable, unique self: ‘the self has taken on the vital role in providing meaning…to life’ (Baumeister 1991:114). Thus, Baumeister (1991:77) links the modern dilemma of self-hood to meaning, arguing that concerns with identity are actually often about wanting life to make sense ‘in some acceptable fashion’.

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[63] For example, Edmondson frames this as a distinction between taking positions about the meaning *of* life and practicing activities that give one satisfaction or meaning, also recognising that the two overlap in that the way people live expresses their opinions about the first. The distinction is similar to Holstein’s (2015:119) distinction between ‘meaning’ in a cosmic sense, and the abiding importance of meaning to all human life and how we think about it in everyday terms.

As mentioned in **Chapter 3**, definitions of meaning in life often identify a number of domains or needs. For example, Dannefer and Lin (2014, citing Deci and Ryan 1985; 2008) suggest that a three-dimensional formulation is common across disciplines - competence, autonomy and relatedness. Taking an empirical, social science approach, Baumeister (1991;2005) argues that meaning is created by individuals as products of society, and identifies four overlapping kinds of meaning, or 'needs' for meaning, sought by individuals to satisfy a meaningful expression of self:

1. **Purpose**: the need to experience that one's life is meaningfully connected with some positive future goal, or inner fulfilment based on developing a personal talent; it can be one thing or many simultaneously;
2. **Value or moral- worth or –justification**: the way one lives can be morally justified, being right, good, legitimate and having positive value;
3. **Self-worth:** that one positively values oneself and is respected by others especially for what one does or can do better than others; this can be acquired through membership in a collective (nation, religion, employment, lifestyle, etc);
4. **Efficacy, competence, or perceived control**: the experience that one has some control over one's life (which he links to a sense of purpose in the sense that without efficacy, goals or purpose would make one feel helpless).

Baumeister (1991) recognised that when a person is not satisfied relative to these needs he/she will be inclined to restructure life through changes in behaviour. Baumeister did not list 'belonging' or 'connection' among the four 'needs', but nonetheless he sees the need to belong as a most basic human need and a motive for meaning-making (Baumeister 2005; Stillman and Baumeister 2009; Baumeister, Maranges and Vohs 2017). Others argue that a dimension of 'belonging,' connection or interdependence needs to be added to Baumeister's framework (Derkx 2013; Baars and Phillipson 2014). Derkx (2013) expanded on Baumeister's four needs and also applied them to the issue of meaning in later life (2016). As well as adding the need for connectedness, which can be connection to other people or involve connection to 'the impersonal other', and excitement, he adds the need for comprehensibility, which he links to Baumeister's fourth need - the need for control, in the sense of interpretive control, or the need to understand the world and explain what happens to us (Derkx 2013:46;2016).

As Derkx (2013) argues, Baumeister's four needs could be compressed or expanded. They might (with the addition of a 'belonging' domain) be compressed to correspond with Deci and Ryan's (1985; 2008) self-determination framework – competence, autonomy and relatedness. As I said already, I did not use this or any 'meaning' framework as part of my inductive analysis, but in order to discuss participants' accounts in this Chapter, I use Baumeister's domains of meaning. I do so because they are consistent with other frameworks, and the 'needs' or domains are useful in bringing specificity to the analysis of participants' accounts. I also consider the need for connection or interdependence as Derkx (2016) and Baars and Phillipson (2014) suggest.

9.1.2 Meaning and Later Life

In **Chapter 3**, I discussed approaches to meaning in later life within critical gerontology (especially moral economy or cultural approaches). While recognised as an important issue in older age, meaning is seldom discussed directly. And Laceulle and Baars (2014) suggest that stereotyping cultural narratives of ageing (decline or age-defying) deprive older people of meaningful frames of reference. Baars (2017) argues that an emphasis on 'hectic adulthood' can suggest that life becomes less meaningful and residual in older age.

Sources of personal meaning were found to be generally similar across age-groups in an Australian study (Prager 1996). But Thompson (1992:39) characterised older age as a time of 'constant reconstruction', arguing that increasing age involves having to face difficulties in doing so. Thus, the challenge of self-realisation or actualisation is likely to grow with age (Dittman-Kohli 1990; Thompson 1992; Bauer and Park 2010; Dannefer and Lin 2014) and with disability onset (Murphy 1987).

Baars and Phillipson (2014:17) consider Baumeister's four needs in light of ageing – when the 'time horizon of life' is gradually changing. While arguing that ageing is a 'normal' part of life they suggest that it has some typical characteristics that 'deserve articulation'. They suggest that this may give Baumeister's first 'need' – for a sense of purpose – some particular dimensions, such as a sense of urgency, but may also create a feeling that it does not matter what one might achieve. On the other hand, they suggest that an awareness of finitude may make ageing people appreciate the uniqueness of people/situations more deeply, and that ageing can confer a sense of self as part of a larger process that continues after one's death. They also suggest that issues such as moral-worth and self-worth may become more difficult to maintain if older people are seen as a burden to their society or culture.

I mentioned that there were few empirical studies exploring meaning with older people. A much-cited one from Thompson (1992) describes occupation/leisure and relationships as the spheres of activity in which elders find meaning[64] and suggests that the greatest threat they face is loss of purpose and boredom. Addressing the third age, Weiss and Bass (2002:9) identify these same areas (engagement and relationships) as key, characterising the challenge of leading a life perceived as meaningful as the search for occupations and engagement that provide 'lives of authenticity and richness and value'.

These two areas (occupations and relationships) are also those I identified as key areas of challenge to meaning in life for participants in this study. Thus, this study suggests that these two areas are important not just to those in the 'third age' but also to participants who can be considered to be in the fourth age, and to those who are ageing having lived with life-long disability. There is little/no exploration in the literature focusing specifically on how older people who experience disability (or are considered to be in the so-called 'fourth-age') construct meaning in life.

9.2. Challenges to Meaning: Uncertainty, Losses of Occupations and Relationships (or 'how do you diminish the grimness of just sitting there doing nothing?')

I now turn to present and discuss findings. The majority of this Chapter presents and discusses findings about how participants responded to processes of disablement – something that they experienced as intertwined

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[64] He characterised them as four spheres - work/occupation, leisure, grand-parenting and intimate adult relations

with losses of people and of connection to social groups. In this section I first briefly discuss how ongoing uncertainty, losses of occupations and of intimates and connections could cause challenges to perceptions of life as meaningful. The findings I outline in this section apply to those experiencing disability with ageing (DwA) and also to those ageing with disability (AwD) whose impairments often worsened. They also involve recapping to an extent on the findings of the previous two Chapters.

As I showed in **Chapter 7,** a key consequence of disablement onset (or worsening), as participants perceived it, was a heightened sense of finitude, a sense of uncertainty about everyday life and the future, fears of dependency and of change in social relationships, and losses of occupations/activities. Another could be experiencing environmental barriers to participation and a sense of being consigned to a discredited social category or ‘second class citizen’, something experienced for the first time in older age by the DwA group (as I showed in **Chapter 8**). Processes of disablement could mean having fewer connections to communities and smaller networks, and simultaneously participants often experienced loss of close family members (or illness/impairment amongst them). These losses could also be partly constitutive of disability (see **Chapter 8**). This amounted to a cycle of further reducing opportunities for activity and participation and connection with others.

Thus, for disabled elders, loss of people could radically escalate issues caused by impairment and disability, leading to greater ‘confinement’ at home, and compensating for changes could be extremely challenging. This means that threats to meaning are greater for disabled elders than for others, and responding is also more challenging. For example, Josephine (aged 78, DwA), talked of the combined effects of the death of her husband and the onset of visual impairment:

> Josephine (DwA): I was widowed three years ago ….. so I am there in the house on my own most days. Now five years ago I developed glaucoma, sight impairment, so I couldn't get a [driving] licence, so I am confined more or less to the house unless I do something about it.

Like other participants she was experiencing changes in her body, in her activities and in her family – she experienced the effects of these losses in combination – resulting in being ‘confined’. Josephine’s phrase ‘unless I do something about it,’ also suggests how she responded to these challenges. What Josephine ‘did about it’ was to join an older people’s centre, suggesting the importance of public and community responses in providing outlets that enable people to respond to the challenges involved (which I consider in following sections).

Several discussed, with sadness, loss of spouses or other intimates like siblings or adult children. This loomed larger for some than disability onset/worsening, although accounts could combine the effects of the two (See **Chapter 8)**. One consequence was that, for many, days were more confined, mundane and boring and in some cases solitary or lonely. Many participants were not able to get out of their houses alone, or if they did, did not have many places to go. Sometimes visitors were few. Others had family in their lives and their narratives did not suggest that they were lonely, although they sometimes felt they lacked the company of friends and things to do.

A few perceived threats to their mental health from being confined to home. Some said they go out to a shopping centre or café so they can have some contact with others. Tony (aged 83,AwD) described buying cakes in case of having callers, and having to dump them as callers rarely came. Angelina (aged 65,DwA) cried at the thought of being alone in the world, her friends are ‘busy’ and she sees less of them. She experiences confined and solitary days now, when she sometimes opens her door so that passers-by might say ‘hello’. Describing his days, James (aged 83,DwA), who can no longer leave his home without help, says, ‘There is a possibility somebody might call, but it is very rarely’. The death of his wife has caused James great grief. They used to holiday extensively and play bridge and they were part of a bridge community, involving a lively social life with weekends away. He still plays weekly bridge with his brother who collects and takes him, but his brother’s health now concerns him – another loss that James fears. This indicates the kind of uncertainty that many participants live with (see also **Chapter 7**), and how a life no longer linked to key intimates could also mean having fewer participation outlets.

As argued already, worsening impairment with ageing could have similar consequences for the AwD group as for others. Of course, both groups can experience deaths or illness amongst families and friends. Thus, Hazel (aged 80,AwD) said she doesn't like ageing. She identifies the 'lack of independence' as its worst aspect and her husband's death means she finds everyday activities and social occasions more difficult now. For Simon (aged 66,AwD), 'everything has changed' since the death of his wife. He said he hasn't been on a holiday since her death, and he has not been bowling either: 'I have nobody to do it with'. Sheila (aged 61,AwD) was widowed in her 40s, and subsequently had a good friend (made through annual trips to a respite centre) with whom she used to socialise and have great fun, but she said:

> Sheila (AwD): About three years ago she died and I really miss that, not having somebody.

She is often alone at home now and increasing impairment means she can be frustrated in trying to do things. She said: '…at home sometimes you get so frustrated and nobody is there, I could end up in tears.' For this group, especially, there could also be a sense of loss of a key advocate or champion – say a mother or sibling. For example, Teresa (aged 87,AwD) said, 'my sisters made life good for me', but now, 'there is not really anyone'. That being said, she also identified the Coordinator of the Older Person's centre that she attends as someone who improved her life – and this again signals the important role in helping to compensate for losses amongst people that community centres/ networks can play.

For members of disability or older persons' centres, attendance could be the only ones in their week – associated often with centres providing almost the only transport they could access. Thus, Francis (aged 76,DwA), relies on a disability centre bus to get him out of home and used the words 'monotony' and 'dull' of days at home:

> Francis (DwA): Now when I go home on a Wednesday evening, that's it. That's my outings for the week. If I don't come here [disability centre], I go nowhere.

Due to gradual onset of visual impairment, Colin (aged 88,DwA) has had to stop reading, going to art-exhibitions and (largely) using his computer: 'All the things that I used to do are gone…' And many friends have died – a former colleague who he had arranged to meet for lunch died the day before our interview. He feels the loss of people and things he used to do since retiring, and he feels an emptiness in what is available to him now: he is bored and lacks a sense of purpose:

> Colin (DwA): But there's nothing to look forward to, that's the problem. It's just how do you diminish the grimness of just sitting there doing nothing.

All of this change involves disruption of the taken-for-granted and a fundamental rethinking of biography, involving a potentially damaging loss of control and altered social relationships, and threats to one's sense of self as an autonomous or contributing person.

Importantly, for the argument I make in this study, Bury (1991) suggests that efforts to cope with impairment onset can be about seeking to have a life that has value and meaning. And Baumeister (1991:77) suggests that perceiving threats to identity can also be about wanting to have a sense that life makes sense or is meaningful. In **Chapter 7**, I discussed some of the ways participants responded to the challenges involved, specifically how they tried to maintain functioning and often also shifted to focus on what they could still do. As I argued, these are efforts to cope by trying to minimise symptoms (through efforts to improve functioning), and by bracketing off the impact of impairment so that the effects on identity are minimised. I suggested that recourse to a 'decline ideology' could help impose meaning on threatening events and buffer a sense of identity. In **Chapter 8**, I suggested that for the AwD group, the 'normalisation' that they experienced with ageing could be associated with taking up activities in communities – sometimes with groups of older people – and doing this helped them to perceive that aspects of life had improved or had more meaning. Conversely, I showed how the DwA group perceived being consigned to a discredited category by others when they started to use mobility aids and other devices, which they could resist and try to address; implicit in their resistance was an assertion of their sense of worth and that their lives had value.

They were involved in ongoing processes of interpretation and reinterpretation. That they were experiencing threats to a sense of meaning in life is evident when you consider that the changes involved also mean fewer spheres in which one can exercise a sense of efficacy, challenges to fill time or to find something enjoyable or worthwhile to do, and consequently to do things that confer a sense of self- or moral-worth. Additionally, all of this reduces opportunities to interact with others, and (for many) the simultaneous loss of intimates and friends causes grief as well as a cycle of further reducing engagement and participation opportunities resulting in a sense of social isolation for some. These amount, I suggest, to threats to perception of life as meaningful. Thus, the changes participants experienced forced change in how they gave meaning to their lives (Thompson 1992:27; Holstein 2015) and that is the focus of the rest of this Chapter. I present findings focusing on responses to the challenges of disablement processes, often accompanied by losses of people, the third main category I identified through an inductive analysis. Taken with the other two main categories I identified, this supports the overarching concept of this study – seeking to remake lives that make sense.

9.3. Responding through Activities, Participating and Connecting

I turn now to discuss actions taken in response to change – which was in essence an effort to remake a sense of meaning in life. Perceptions of impairment and ‘decline’, exclusion and marginalisation, and losses of intimates could exist in parallel with efforts, not just to maintain and improve functioning, or to maintain activities of daily living, but also to participate in activities and communities and to maintain or make connections with others. According to Thompson (1992), loss of intimates represents the greatest challenge in later life. This study suggests that this has greater consequences when later life involves disability (whether experienced for the first time then or experienced as worsening). Furthermore, as Litwin and Levinson (2017:17) suggest, losses of either activities or relationships may mean seeking to compensate in the other area.

In this section, I discuss the effort and creativity involved in participating in activities and the meanings made of some of the challenges involved in these processes. I argue that participants were often actively engaged in a process of reorienting towards lives they perceived as more meaningful. The effort involved in the simplest task could be striking and, of course difficulties could be compounded if people were without social or financial resources to compensate, including if they did not have access to facilitative public/community services as already discussed in **Chapter 8**.

9.3.1 Investing Everyday Activities with New Meaning (or 'still capable of doing something')

Participants were involved in working around various barriers to carrying out activities associated with daily living like housekeeping, cooking or shopping. Active planning and effort often characterised the simplest daily tasks. In this context, daily activities took on a new significance related to having a goal or a sense of efficacy or connection with others. They could also help maintain a sense of connection to former routines and identity.

Everyday tasks could represent a meaningful goal in the day, help structure time, connect one with others, and call up creative responses. For example, Joan (aged 86,DwA) unpacks her car using her rollator to carry her shopping bags in 'instalments', a process she finds exhausting, but shopping is: 'a very pleasurable part of my week'. Family would do it for her, but she does it, as it provides a purpose and it is sociable ('the people you meet in the supermarket, you've people to chat to'). Similarly, William (aged 70 DwA) describes a daily outing to a local shop using his rollator, which he enjoys because: 'People are very nice like that, always talk. I enjoy that too'. Stephen (aged 88, DwA) likes to do his own shopping so neighbours drive him to the supermarket where he leaves his rollator outside and walks around using the trolley instead: 'I am all right if I am holding a trolley'. Others, including Gloria (aged 80,DwA) described a similar process: 'at the supermarket with the trolley you drape yourself over, which is very handy'.

Participants who would not accept help with tasks described wanting instead to have a sense of efficacy and control about them – as well as something to fill the time. For example, Colin (aged 88,DwA) regrets not shopping or doing the washing-up now as: 'it was an activity for me'. About wanting to do the washing up, he said he wanted to continue to make decisions and to do what he could for himself:

> Colin (DwA): So other people doing everything for me wasn't a solution to anything, I had to do some things for myself, I had to make the decisions that I wanted to make.

Thus, participants maintained a sense of continuity with the past through ordinary routines, ‘the mundane and comforting sameness of repetitive activities give structure and logic to people’s lives’ (Becker 1998:4). And everyday or mundane activities took on a new significance as they became difficult or threatened (Reed, Hocking and Smythe 2010).

Even seemingly small tasks like sorting medicines could be imbued with significance. Francis (aged 76,DwA) regrets that there are many things he cannot do – especially jobs around the house. But doing what he can still do takes on ever greater significance, such as sorting his monthly medication, which he says he does ‘to keep my mind a bit active’ and to feel ‘still capable of doing something.’ Thus, he understands this task as an effort to maintain mental functioning and to have a sense of efficacy. This can be characterised as seeking to meet two of Baumeister’s (1991) four ‘needs’: the need for a sense of efficacy and control, and a future-orientated sense of purpose (maintaining functioning by keeping the mind active).

Overall, participants demonstrated determination and creativity in meeting challenges involved in everyday activities, which could be understood as giving a sense of purpose and efficacy, and as conferring a sense of self-worth, and perhaps moral-worth (in the sense of doing something that others might deem worthy), and thus to fulfil the four ‘needs’ for meaning identified by Baumeister (1991). They could also be understood as a way to connect with others, also associated with having a sense of living meaningfully (Stillman and Baumeister 2009; Derkx 2013).

9.3.2 More Meaningful Lives through Participation and Engagement: (or ‘the singing makes you happy’)

As well as meeting challenges of daily living, participants often maintained and took up opportunities for participation and connection. Some described participating in activities to help structure the day, and not only to pass the time but to connect with others and to have a ‘focus’ or ‘goal’. Just as with maintenance of daily activities, an amount of effort could be involved in maintaining ways of participating in communities.

Tony (aged 83,AwD) drives but describes getting in and out of his car with his rollator as increasingly difficult. But he attends daily Mass, which he (and other participants) valued for its sociability and for the structure it gives to a day:

> Tony (AwD): It is a goal you have and it gets you up in the mornings and I kind of use it for exercise if you know what I mean.

Joan (aged 86,DwA) is still engaging in several long-standing activities despite the effort involved. Her experience of singing with a church choir illustrates the motivation for continuing. As she describes it, accessing the choir gallery is painful, takes time and involves risks of falling. She strategises – getting there early so that she can climb the stairs without delaying others. To do this she leaves her rollator downstairs and takes a stick, relying on there being someone there early who can take the stick up for her so that she can use both hands to pull herself up the 22 steps: ‘Oh to think of those steps’. She weighs this effort against the enjoyment in the activity:

> Joan (DwA): Like the last thing you want to do, say is go out to choir practice. But coming home you’re glad you did. It makes you happier. The singing makes you happy. The interaction with others - the friends you’ve made there – you know in that situation - that makes you happier. So all these things are the good sides of it and worth making the effort and worth going through, you know, putting up with the downsides of it.

Singing continues long-standing routines, connections and fun, and she balances its challenge with its contribution to her life.

Several engaged in learning and education and, again valued these outlets for sociability and for the sense of efficacy and self-worth it confers. Asked what made her life good at present Liz (aged 55, AwD) said:

> Liz (AwD): Mixing with people, getting out and about and mixing with people. And sort of feeling... I love when I make something

> and bring it home for someone and they like it…….. I love learning anything, I love education.

Alice (aged 72,AwD) became passionate talking about learning to paint/make art when she started attending a disability centre within the past 3 years, communicating a sense of growing self-worth and indeed of purpose in the sense of providing subjective fulfilment:

> Alice (AwD): One great achievement for me is art, doing the painting, because I never knew in my heart or soul that I could do anything like that or be good at it. I remember the first picture I painted.... My family cannot believe it, I can't believe it myself to be honest.

For a few, the fact that they have reached a certain age, which they associate with a shortened event horizon, was a spur to action consistent with the contention of Baars and Philipson (2014) that a shortened event horizon can confer a sense of urgency. For example, Julie (aged 80,DwA) said of reaching 80: 'putting things on the long finger …..is probably not a very good idea.' She is using that as a spur to self-publish short stories to raise funds for charity.

Participants' accounts of change often focused on decreasing involvement in informal, community organisations, where, as Holstein and Gubrium (2000) argue, people seek meaning for their lives. Several participants' accounts illustrate agentic, creative responses to change. For example, following his wife's death, Simon (age66,AwD) thought he should get involved in community-development groups:

> Simon(AwD): I thought I had better start getting involved in things…… rather than sitting here every day on my own.

He does this even though he finds it difficult to get around without his wife – both visually impaired, they had functioned together, but she had more sight than him and it is much more challenging for him now to do things that require him to go out alone. But he still does it.

Stephen (aged 88,DwA) regretted various activities that he cannot now do: he misses his walking group 'terrible'; he also misses dancing, which he did with his deceased wife. Much of his narrative focused on things he had achieved for his community after he retired, on the one hand, and his wife's loss, on the other. He talked about still being on the management committee of his local community centre but said that he is not the 'brains' any longer:

> Stephen (DwA): Before, if you like to say I was the brains. I am not the brains now but I am one of the committee. Before I was able to get my way…speak my mind. But they still respect me like that and they rang me to make sure I'd be there.
> Interviewer: And what is different about the way you feel about yourself in that situation?
> Stephen: I have realised that I am old. I have realised now that I am old and I am not the [Stephen] that was. And I know the sons are worrying about me. I don't like them worrying about me but I know like that death is not that far away I feel. If I hit 90 I think I will be doing well you know.

At one point Stephen had talked about no longer being physically able to be involved in the day-to-day running of the centre. That, and distancing from the decision-making of the committee, appear to be key parts of his experience – although it is not clear why or how the latter has happened. There is a combined sense of being changed physically and in his capacity for exercising influence, and a sense of finitude. He feels like a changed person – 'I am not the [Stephen] that was'. Simultaneously, within the past two years, he is grieving and living alone the first time since his early 20s and his reference to his sons' concern for him suggests anxieties about autonomous functioning and about being perceived as dependent.

But Stephen stresses continuity in his involvement too, and in how the committee members still 'respect' him. He is not entirely a different person – though there has been disruption and challenges to his sense of self. Stephen's valuing of his continuing community role can be interpreted as involving connection to others and his community. Furthermore, in terms of Baumeister's (1991) needs for meaning, it confers a sense of purpose and efficacy (an area where he can improve things), and self-worth and moral-worth (doing something he considers valuable and where others 'respect' him). Thus, despite experiencing significant loss and challenge, his community role helps him perceive continuity and, in short, that his life is still valuable and has meaning.

Even where participants' main outlet was focused around attendance at care centre(s), several framed their approach to activities ('you know, have to keep yourself active') in ways suggesting identification with what Timonen (2016:64) calls 'model' ageing (meaning 'successful' ageing, third-age and cognate concepts). Thus, those who 'deviate' from 'model' behaviour may nonetheless evince behaviours and attitudes consistent with them (Timonen 2016: 64). The findings I present in this Chapter suggest that at least one reason for this is that the goals that these models typically engage with are considered valuable by disabled older people. These goals include self-development, remaining active and socially connected (Laceulle 2016) and these would seem to resonate with participants (as argued already) because they did not define themselves by their bodies or their impairments and because they want lives they value and that have meaning.

Critical gerontologists point to limitations of the third age discourse, such as its disregard for the structural power factors influencing successful realisation of its ideals, and its alignment with the stereotyping anti-ageing industries (Phillipson 2013). All of this suggests the need, as Laceulle (2016:312) argues, to develop narratives that aim to both recognise the potential for growth and flourishing with age *and* provide people with resources for a meaningful integration of existential vulnerability. It also points to the need for societies to find ways of enabling disabled elders to stay involved in communities in ways they find meaningful.

9.3.3 Reflexively Seeking Something 'Meaningful' (or 'It shouldn't be something that you're just doing')

In **Chapter 8**, I showed how the DwA group often asserted a sense of their worth in response to being consigned to a discredited category by others (summed up in Francis's phrase, 'they can take me as I am or forget about me'). Joan (aged 86,DwA), who perceived that others now consigned her to a discredited category (or as 'other', see **Chapter 8**), responded by characterising herself as full of life. She used the term 'brimming,' and instanced a range of activities and plans:

> Joan (DwA): Don't define me by my disability or don't define me by age. There's a lot more to me than all of that. I'm still brimming with

> ideas all the time. Absolutely brimming. I'm coming up in my head with themes for poems. Eh….with ideas for...I think about having parties. I want to have….I want to put a garden room out there [pointing] because I want it to be perfect for parties……I want to gather them all. I love...there's nothing I like better than the whole family being here around and just having the craic.

Joan's account suggests personal goals (writing poems) and plans for parties and 'craic' that involve her whole family (which is a large one). In her account, Joan is far from the kind of stereotype of a passive older person, experiencing 'decline' in her 'fourth age', acted upon but not acting and just needing unchallenging activities that pass the time.

Others did not talk about feeling discredited, but could be reflexive about the impact of losses of activities/participation. They could also talk about the opportunities they still sought and could see them in terms of conferring meaning in life. For example, Sheila (aged 61,AwD) made a distinction between services that 'keep you alive' and those that 'made you feel like you were living', the latter being ones that included fun and changes of routine – though she found that there were fewer of those available to her now due to cut-backs in services.

Colin (aged 88,DwA) was reflexive about seeking things to do that he finds 'meaningful,' to use his own term, and I quote from him here at some length. Experiencing visual impairment, Colin has had to stop reading, going to art-exhibitions and using his computer: 'All the things that I used to do are gone and, therefore, I have to find new things'. He brings initiative to this task and wishes to make his own decisions without which he feels he would not be living 'in a meaningful way':

> Colin (DwA): It is not to be... it's not when you are geriatric [laughs]...you have to have people advising you all the time. You have to use your initiative or you are not living in a meaningful way.

He was passionate about finding things to do that he characterised as 'meaningful', which he described as: 'something which I considered worth doing and which would leave a trace of some sort'. Colin came back several times to the difficulty of finding something 'meaningful,' describing his worsening eyesight as causing difficulty finding things that he values doing:

> Colin (DwA): It shouldn't be something that you're just doing, trying to…escape. [gives an example of physical exercise]. So, the trouble is to find meaningful activity. When you can't see it's very challenging. And that's why…apart from the radio, the television and the computer [pointing to the iPad], I don't know what I'd do. But even that is difficult because as my eyes get worse.

Colin says he is 'inventing things to do' and spoke with enthusiasm about using his iPad to look up things and for music ('I still find that I listen to a bit of Mozart or Duke Ellington and I vibrate to it, it makes me feel good'… 'I'm discovering things that are answers to questions that I might have had 50 years ago').

Colin demonstrates that it is important to him to have a sense of control as he describes how he 'practices' for being totally blind:

> Colin (DwA): I try to do as many things as I can by touch. For example, every day I eat a banana which I slice up. And I slice it without looking at it. And that's a good exercise. Doing things like that. Well it helps you deal with the world around you…….. But I am doing really well all the time I'm dealing with things. I'm keeping up. I could find my way up and down the stairs into different things.

Thus, Colin describes a reflexive process of meeting a dynamic bodily situation, and reduced opportunities for activity and participation, with attempts to maintain a sense of efficacy and control and to have a purpose. This is somewhat similar to how others engaged with the anticipated necessity of moving to a nursing home, though they could not control when or how it would happen (see **Chapter 7**). Thus, life change for these participants is dynamic and complex and they are constantly interpreting and reinterpreting their experience within their contexts.

However, despite his ingenuity, Colin's worsening sight means that he is challenged to find things that he wants to do – he longs, without finding it, for something 'significant' to do. He also feels that if his functioning deteriorates to the point where he is 'not able to do anything' there will be no point in living:

> Colin (DwA): Now it is very challenging because I am trying to think of what next to do and I can think of little things but nothing significant. Because I can't use my computer properly or anything, I

> can only barely get simple things on that [points to iPad]. I wouldn't particularly like to live on because what is the point? The less you are able to do, I mean if my hearing goes and if I am not able to do anything, I don't call that living.

So, despite his ingenuity, Colin has reached a stage where he is finding life very challenging – he has a reduced sense of interpretive control (Derkx 2013; 2016) despite ongoing efforts to get to grips with the way his world has changed. Colin is trying to live a life which he perceives as ‘meaningful’, expressed especially in his attempts to improve his sense of efficacy and control over his situation and trying to find a sense of purpose. He perceives as ‘meaningful’, activities that are not just about filling time, but that engage him fully. Colin is seeking activity with a deeper meaning, which, according to McGuire, Boyd and Tedrick (2004) requires some dimension of growth or personal development. Writing about how people in the third age can be challenged to find things that make them feel ‘fully engaged’, Weiss and Bass (2002:6) describe one man as follows:

> He wanted engagement to which he could give himself whole-heartedly. He wanted to engage in an activity that others would recognise as valuable, that might even make a difference to them as well as for himself.

This characterisation of someone in the third age is also precisely how Colin describes his needs in relation to engagement. Thus, this is a challenge of the so-called fourth age (as well as the third) and at that stage it is also a challenge that is harder to meet.

Heikkinen’s (2000:474) suggestion that bodily changes can be so profound as to thwart ability to find meaning in life is echoed in Colin’s words. His words also show an imaginative engagement in that event horizon – he is not a passenger on this journey – he is reflexively engaged in anticipating and preparing for it. Colin’s account simultaneously displays vulnerabilities and limitations *and* creativity and determination.

But contextual factors are also relevant. Not every participant has the kind of resources, education or interests that Colin has. I have already discussed in **Chapter 8** how access to appliances and technology is unequally divided, with social, cultural and financial capital having a bearing on who has access. For example, his familiarity with and access to an iPad allows Colin an outlet that others lack. On the other hand, there are other ways that Colin may be disadvantaged relative to others. For example, despite liking to use technology, Colin does not in the main use technological adaptations that could now help him. Whereas others, including visually impaired people amongst the AwD group, used a variety of assistive technologies. This suggests that within certain pockets of the disability sector there is knowledge and resources that if shared more widely could help more people, and the need for access to technologies to become more widespread.

9.3.4 Experiencing Positive Connections and Contributing (or it keeps me 'very much alive')

It is important to note that participants' experiences were not all of loss of relationships or loss of a sense of connection. Even if spousal or other losses caused suffering, some participants talked about other positive relationships - with family, neighbours and friends, and especially with adult children and siblings. Warm relationships with adult children were highly valued. For example, April (aged 65,AwD) described her daughter as 'my best, best, best friend' and said that children/grandchildren 'keep me going'. Similarly, for Edward (aged 68,DwA) having contact with children and grandchildren 'keep[s] me very much alive'. But several also wanted relationships with 'outsiders' too – even if adult children were supportive, having other relationships mattered.

Participants contributed to the lives of family members financially and otherwise. For example, both Alice (aged 72,AwD) and Una (aged 65,DwA) helped to look after teenage/adult grandchildren with intellectual disabilities. June (aged 82,DwA) planned and saved for months to have presents for each child and grandchild at Christmas. Participants could be both recipients of care and also carers. For example, Annette (aged 84,DwA) was caring for her husband with dementia, while also a son who lives with them cares for both.

Participants also occasionally recounted very warm relationships with carers provided through public services, sometimes perceived as going beyond the strict bounds of their roles, and who provided long-standing support. This was valued by all and was especially important to participants whose family support was small. For example, in Carmel's case on an occasion when she fell from her wheelchair and could not get off the floor, it was her carer who she phoned, not a relative.

Religion was not perceived as important to everyone, but it was very important to some participants. Consistent with Derkx's (2013) characterisation (see above), some communicated a sense of connection conferred by religious practice. It could involve routines that connected them with other people. Thus, Patricia (aged 90,AwD) said of daily Mass, 'you'd be missed' if you didn't go. Others said their faith was a support (even if they didn't practice) and associated it with a more transcendental connection. For example, for June (aged 82,DwA) religious faith meant she had a constant sense of connection: 'No matter what happens to me I ask him [Jesus] first'.

I suggest that these relationships (both personal, with carers and associated with religion) signal to people that they matter and thus were significant in maintaining a sense of having a valued self and a life perceived as meaningful.

9.4 Community Organising and Public Policies Helping Participants to Perceive their Lives as Making Sense

I move on now to present how participants often perceived positive changes in their activities and in their sense of connection to their communities where this was facilitated by centres where they could go, often facilitated because they provided transport. This highlights the important role for systemic public and community responses to the impairment-related changes of older age.

9.4.1 Helping to Address Losses of Activities and People (or 'a big change, the company that is here')

Most study participants were drawn from attendees at disability and older people's centres and they talked not only about lack of company and boredom as having motivated them to start coming, but also about loving the centres and looking forward to coming. Several spoke enthusiastically about the change that attending care centres had brought, associated with company and activities – and I already discussed some instances of this in **Chapter 8**.

For Josephine (aged 78,DwA), who I quoted at the beginning of this Chapter, the decision to join a group followed as a direct consequence of visual impairment onset followed by bereavement (of a husband who used to drive). She benefitted from having a state-of-the-art older person's centre near to her that provided an outlet – giving her both new people to meet and activities that she enjoys (singing with a choir, for example). She now gets lifts from other members to attend events, and the centre also provides an accessible bus. It has also connected her to her community more, in turn conferring a sense of belonging and of being able to contribute. For example, on the day I interviewed her, Josephine was arranging to go with others to 'support' a teacher at the centre who was putting on a play.

Centres/Disability organisations could confound expectations and provide a sense of belonging that participants valued, as well as enabling them to learn and engage in enjoyable activities. Peggy (aged 83,AwD) refers to starting to attend a disability centre, which she did some 16 years previously, as 'a big change, the company that is here'. June (aged 82,DwA) described a life that had become largely confined to home until she joined her local disability centre, which she did two years previously. She enjoys not just the activities at the centre, but evening outings for films and meals:

> June (DwA): And it has changed my whole life. That's what, two years ago. I come in that door and I am home. I live for it a few times a week….. I came in and from the day I came in, the same thing, and honestly, I wouldn't miss a day unless I really have to.

Francis (aged 76,DwA) describes how the disability centre he attends confounded his low expectations – he very much values having learned to use a computer there and he now uses one at home as well. Several used words like 'at home', 'just like home' or where you 'belong' to describe how they felt accepted in coming to a disability centre or an older people's centre, conveying a sense of having discovered, or re-discovered, a sense of connection and community. Social exclusion reduces perceptions of life as meaningful (Stillman *et al*. 2009:692) and gaining a sense of belonging helped with perceptions of lives as meaningful.

Positive perceptions of joining centres occurred amongst the DwA and AwD groups. Amongst the latter, Teresa (aged 87,AwD) and Alice (aged 72,AwD) both talked with delight about meeting people when they joined an older person's and disability centre, respectively. For Alice, coming to a disability centre three years previously: 'has been fantastic, been a great outlet for me, meeting the people' and it has also introduced her to painting, which has surprised and delighted her.

Timmy (aged 78,DwA) describes those attending lip-reading classes as 'my new social circle'. He reflects that it may be 'wrong' to only be with 'hard of hearing people', and adds:

> Timmy (DwA): They understand me like I understand them. And they make allowances for the condition we have.

And Rory (aged 68,DwA) praised the staff of the disability centre he attends and said: 'I mean they let you believe there's nothing you can do wrong. And it's a great feeling.' Implicit here is a sense that being disabled, even when older, can feel like doing something 'wrong' in some situations. Also, these participants seem to perceive an element of 'normalisation' through contact with others having the same experience or with centres where disability is not treated as exceptional.

Perhaps it is surprising, given that participants such as Timmy, June and Rory have experienced disability only later in life, that they should have such a sense of identification with or belonging in disability groups and centres. This is so, considering how a 'disability' identity is less likely to occur on the part of older people acquiring impairments in late life. Their accounts echo how Wendell (1996:27) described having a sense of no longer 'struggling alone' when she connected with other (younger) disabled people. The ease and satisfaction expressed may be associated with the relative difficulty of negotiating life generally or with perceptions of prejudice or othering by non-disabled people (see **Chapter 8**). It may also be associated with a paucity of places that you can go for any kind of communal experience if experiencing impairment, particularly if, simultaneously, your life is not well-networked due to loss of family members/friends.

This demonstrates how important are systemic responses to the experiences of disability in older age, often experienced simultaneously with losses in families and social networks compounding the difficulties for the people involved and meaning that their participation cannot be left to the families, friends and neighbours (as argued by Litwin and Levinson 2017:17).

9.4.2 Critiquing Centres that Didn't Challenge (or 'You need something that is going to encourage you to come out')

While there was great appreciation of what disability and older people's centres offered, this could also be tempered by criticism. Participants' criticisms shed light on the degree to which they valued opportunities for participation that stimulated or challenged them. They sought not just to pass the time, but also to perceive that what they were doing was in some sense worthwhile or meaningful.

For example, participants sometimes praised the staff/volunteers of centres and valued the opportunities for socialising, but critiqued the quality of activities offered. Rory (aged 68,DwA) characterises activities at his disability centre as sometimes not challenging enough. Hazel (aged 80,AwD) enjoys sociability and activities at the disability centre that she attends ('active and more going on'), but critiqued a centre she used to attend. Peggy (aged 83,AwD) talked about loving some of the activities in the centre she attends – the craft-based ones - but she critiqued the standard of teaching, which she experienced as uneven. Josephine (aged 78,DwA) praised the purpose-built older people's centre that she now attends and contrasts it with other clubs/centres for older people both for the limited range of what they offer and for their lack of 'comfort', their bleakness and dreariness:

> Josephine (DwA): I mean the place in [name of town] is the old school, it is cold and you have the old toilets that were there when the kids were there in the school, you know what they are like, and the facilities are not there……The old folk go there a couple of days a week and they have meals. … And they could have bingo, they could have art classes, but the surroundings are dour and it doesn't lend going out of comfort and going into... You need something that is going to encourage you to come out rather than somewhere that is going to be bleak and dreary.

Thus, there is little sense that participants were passive recipients of care in the centres they attended – rather they were clear-sighted about strengths and weaknesses of the surroundings and of the activities. As well as connection with others, what they seemed to value most were opportunities for self-realisation or individual development and comfortable surroundings were a necessary prerequisite.

9.4.3 Opportunities to Contribute (or 'I go there to play music, but I am part of them myself')

Weiss and Bass (2002) identified being of service to others as a way of investing lives with meaning in the third age. However, this study's participants (who can be categorised as in the so-called fourth age) also talked about contributing or wanting to contribute to families and more broadly – and this too helped them to perceive that their lives had meaning.

They explained their motivations as both wishing to express caring or connectedness or considering it worthwhile to do, conferring a sense of purpose or self or moral worth in a culture that can frame older disabled people as a burden. Thus, community groups that include disabled elders in opportunities to contribute help them to experience their lives as meaningful. For example, Gloria (aged 80,DwA) continues to work with her local Meals on Wheels service, and June (aged 82,DwA) likes to be able to continue to contribute to charities (by buying their calendars as presents for family members) even though she can no longer do fundraising for them as she did in the past. April (aged 65,AwD) volunteers with a telephone help-line for people affected by polio – wanting to contribute to others having similar experiences to her, and Babs (age 67,AwD) likes to give talks to students of social care about her experiences as a disabled person, 'because if we don't get up and talk no one will know, you know'.

Care centres sometimes provided opportunities for contributing. A few participants communicated a dual sense of their attendance at a centre – as a member/client and as a volunteer. Several helped provide entertainment or contributed in another way. Thus, they asserted a status and identity – as an active contributor – while also being a recipient of care

– in this way, they may also have been resisting societal framings of older people as burdensome. For example, Tony (aged 83,AwD) communicates his sense of having a dual role at a day centre: ‘I go there to play music, but I am part of them myself, you know’. And Kathleen (aged 85,DwA) joined an older people’s club when she was asked to come along to sing for the members. She sings regularly, feels that others enjoy this and described how: ‘That does keep you going’. Thus, she asserts her value and identity as an entertainer as well as care-recipient.

Overall, I suggest that the accounts discussed in this section amount to participants responding to challenges in ways that suggest they are seeking to live lives they perceive as meaningful through activities, participation, connection with and contribution to others.

9.5 Discussion

In this Chapter, I recapped on my arguments that participants’ attempts to cope with disablement processes were attempts to perceive that life had value and meaning (from **Chapter 7[65])** and that reactions to both ‘normalisation’ and othering processes (experienced, respectively, by the AwD and DwA groups) showed that participants sought lives that they perceived as having value and meaning (see **Chapter 8[66]**). In the main part of the Chapter, I showed further ways in which participants responded to the challenges involved in disablement processes, which often occurred simultaneously with (and were partly constituted by) loss of intimates and reduced social circles, creating a cycle of ever-fewer participation outlets and connections. Both could reduce perceptions of life as meaningful and in combination they were particularly challenging. Thus, the changes that participants experienced forced change in how they perceived meaning in their lives and often forced them to act in ways that shaped their lives to be

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[65] By for example, minimising effects on identity by trying to maintain functioning and focusing on what they could still do or by attributing a cause (‘decline’) or meaning to their experience.

[66] The AwD group could take up activities in their communities, helped by the ‘normalisation’ with ageing that they experienced, and doing so helped them to perceive that life had improved or was worthwhile and more meaningful. Conversely, the DwA group could resist and try to work around their perception of exclusion by physical environments or of being consigned to a discredited category by others, and their resistance signalled their wish for lives that they valued.

more meaningful. Coping with change involved actions that may be understood as efforts to restore ‘order following disruption’, involving re-working understandings of the self and the world, redefining the disruption and life itself (Becker 1998:4). Informed by a constructionist perspective to the lifecourse, this study revealed that life change meant that they were constantly interpreting and reinterpreting their experience within their contexts (as Holstein and Gubrium (2000:83) suggest of people generally in respect of change). Even amongst the oldest participants, the experience is much more dynamic, complex and agentic than conventional depictions of the last stage of life, or the ‘fourth age,’ suggest. Taken together these three Chapters support the overarching argument of this thesis that participants were ‘seeking to remake lives that make sense’.

In response to change and loss, participants engaged in attempts to shape the activities in their lives and to maintain connections with others, and they invested what activities they could still do with new meaning, processes that amount to seeking to remake lives that make sense. I showed how maintaining daily routines (like shopping or attending Mass) and a range of other activities and participation outlets were extremely important, often undertaken despite great difficulty and often taking on new meanings as they became threatened.

I discussed their accounts in light of Baumeister’s (1991) four ‘needs’ for meaning, together with the need for connection or interdependence (Derkx 2013; Baars and Phillipson 2014). I argued that participants’ accounts can be understood in terms of a search for a sense of purpose, self-fulfillment or comprehensibility (maintaining routines that give a ‘goal’ in the day, delighting in doing things that interested or challenged them), a sense of efficacy (continuing to do any everyday things they could like housework and to make their own decisions), self-worth or moral-worth (doing things that contributed to others, or making things that others could enjoy). Furthermore, my findings suggest that the need for connection with others and fun or excitement was important, seen in the way they valued the social side of mundane activities (like shopping), in how they maintained and developed activities that involved socialising and changes of routine, and in how they valued opportunities to contribute to others. Thus, maintaining activities and finding new participation opportunities were associated with experiencing a sense of a continuous self and with perceptions of lives as meaningful.

Domains associated with meaningful orientations may be interpreted or reinterpreted by older people. Thus, a sense of purpose is understood as being connected to some future goal and to gaining a sense of inner fulfilment (Baumeister 1991;2005), but a question might be asked if this resonates with older people, especially the oldest old, when the time horizon of life is shortening.

I showed that even amongst the oldest old, there could be a future orientation – in fact a shortening event horizon could spur one to fulfil an ambition. For some, contributing to others, such as children’s or grandchildren’s lives, may have conferred a sense of connection to the future, while also helping maintain a sense of self- and moral-worth. Religious practice probably played a similar role, helping with meaningful orientations by conferring a sense of connection, purpose and moral-worth. This is consistent with the argument of Baars and Phillipson (2014) that older people may experience a sense of purpose through an intergenerational or spiritual perspective, or by embracing goals that go further than one’s own life.

But these were not the only future-orientations. Even the oldest participants did not know how much time was left. This meant that they have a future orientation, which was implicit in many actions (such as joining new groups, engaging in new pastimes where they were available) and also in many frustrations (not being able to find anything ‘significant’ to do, finding the standard of teaching in a care centre uneven). A future orientation was also implicit in activities participants hoped would maintain or improve functioning and even mundane tasks, like sorting medicines, could be understood as efforts to maintain functioning and efficacy.

Participants could adjust ways they contributed to others and thus meet the ‘needs’ for self-worth and moral-worth by continuing to contribute to families, communities and charities in different ways. For example, people whose activities and scope for contribution were limited liked to be contributors in settings where they also received care, something that may also have helped to resist societal framings of being burdensome. Thus, the findings contribute to contextualising how Baumeister's 'needs' for meaning remain relevant even to disabled elders.

Where participants found, or continued to participate in, activities they valued and that linked them with others, this was often helped by public/community action. These findings support the contention of Moody and Sasser (2012) that as long as leisure activities remain accessible and meaningful, older people will continue to do them. This highlights the importance of policies that facilitate engagement for disabled elders (see also Carpentier *et al*. 2010). Accounts of some who had very positive experiences of recently engaging in communal activities (including with others experiencing similar impairments and challenges) suggest a positive aspect of later-life with impairment (for the DwA as well as the AwD group) that has not been much explored in scholarship, and points to the need to explore the individual and societal level factors that make this possible for some people and not others.

Overall, I found that for disabled older people similar challenges to meaning occur in the same areas that are identified for people in the third age (engagement and connections - see Weiss and Bass 2002, discussed above). But the challenges are *greater* for disabled elders, due to limitations of impairment, and having to overcome a range of contextual barriers to participation. These included perceptions that others consign them to a discredited social category (associated with impairment onset for the DwA group) with consequent marginalisation for some, even within communities of seniors. In the previous two Chapters, I showed how constructions of ageing and disability are intertwined, and, that while many of the challenges that older disabled people face result from process that are inevitable – bodily change and losses of important others - not all of them are.

Furthermore, the need for meaningful orientations may go unrecognised for disabled elders. This may be contributed to by the link made in dominant discourses (of successful[67], active or third age) between absence of impairment and health, and able-bodiedness, personal growth and engagement (see Lloyd 2015; Gibbons 2016). Elders who do not fit with these models are left outside these frames – although not, I found, in their own interpretations. Thus, goals that are associated with third-age (and similar discourses), including self-development and remaining active and socially connected, were important to participants. However, as Phillipson (2013:49) argues, third age discourse requires significant social interventions if it is to be realised, something that is especially true for disabled elders.

If follows that boundaries in public policies and in socio-cultural discourse between third and fourth ages are not well marked in the interpretations of disabled older people. Thus, my findings also illuminate debates about the fourth age. Participants' thoughts about the future can be seen in terms of suggestions of the fourth age as a 'social imaginary,' an 'event horizon', a kind of 'terminal destination' or 'black hole' (Gilleard and Higgs 2010a:122,123). As discussed in **Chapter 7**, participants referred to death in the future and several found it difficult to address the possibility of a future when they could not care for themselves. Some could only consider this in apocalyptic terms, consistent with the 'black hole' characterisation. Some said they never thought of the future. Arguably, both these approaches were necessary, as Lloyd and colleagues (2014) say, to keep 'on the right side of the event horizon and from being sucked into the black hole'.

However, the accounts of some participants suggest an imaginative engagement in such a future – preparing for a time of becoming totally blind or a move to a care setting. There was a sense of this as ultimately outside their control, but there was also a clear-sighted engagement, involving sadness and vulnerability and also imagination, pragmatism and effort. These participants were not passive, but sought to creatively engage, seeking to exert such control in relation to the future as they could – again,

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[67] Rowe and Kahn 1987,1997 – one criterion for successful ageing is avoidance of disease or disability.

they were trying to make their lives comprehensible, or controllable and, thus, to perceive that their lives made sense or were meaningful.

Thus, these participants engaged in a process of seeking to know the cultural construct associated with the fourth age or ‘social imaginary’, characterised as ‘unknowable’ (Gilleard and Higgs 2010a). And they do so from a social location that can be considered to be already within the fourth age. This suggests that there may be many event horizons and that there can be efforts to imaginatively know, and cope with, each one. Ultimately, I agree with Lloyd’s (2015) reflection on debates about the fourth age, that what matters most is to develop a better understanding of people’s experience. This includes the need to identify social-constructed aspects of the experience, and, as I argued in the **Chapter 8**, disabling environments and disablist reactions of others to impairment are a component in the very construction of the ‘fourth age’ as a time of withdrawal and stepping back.

I suggest that this means that available cultural narratives of ageing are limiting and divisive, and in treating the so-called fourth age as a kind of residual category, they fail to take account of the ongoing work of reinterpretation of change that disabled elders engage in and of their efforts to recreate a sense of meaning in life. They also insufficiently recognise socially-constructed aspects of the third and fourth ages. I agree with calls from scholars for development of counter narratives. For example, Laceulle and Baars (2014) suggest the need for a moral discourse on self-realisation,[68] recognising the ‘intrinsic connection between self-realisation and a search for meaning’. And Cruikshank (2003:23) argues for a shift toward a self-realisation discourse for its potential to extend the growth and development perspective, usually associated with youth, across the whole lifecourse. My findings provide empirical evidence that support the need to develop a counter narrative that recognises the challenges that disablement processes in older age represent for a sense of life as meaningful and the efforts people make in response. They suggest the need for understandings of ageing and the lifecourse that can integrate

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[68] They take care to make it clear that they are not talking of ‘self-realisation’ as it has come to be associated with the third age and with a consumer and leisure lifestyle, and as such can be exclusionary of those lacking material resources or ‘physical capacities’ but also those experiencing frailty, vulnerability and finitude (Laceulle and Baars 2014:40;41).

disablement processes and that recognise both the challenges that these represent and how disabled elders engage in ongoing efforts to perceive value and meaning in their lives.

As well as in scholarship and discourse, I suggest that the findings underline the need for change at the level of policy-making. Public policies that are bifurcated in terms of healthy or active ageing on the one hand and care and dependency on the other, may fail to recognise that common needs for continuing to live meaningful lives subsist amongst all older people. Policies need to ensure that participation opportunities and active ageing approaches are available to older disabled people. As well as socialising, these must include opportunities for self-development and contribution – not just passing time. Also, skills and access to technologies that are available to some disabled people, if shared more widely, could help others to find more meaningful things to do. Facilitating links between people who face similar challenges may also be helpful, as participants experiencing disability (even for the first time in later life) benefitted from contact with others facing similar challenges.

In the introduction to this study, and in the literature review set out in **Chapter 3**, I pointed to scholarship within critical disability studies and critical gerontology that challenges somewhat similar and divisive orthodoxies within the two fields. Thus, critical disability scholars challenge orthodoxies that deny bodily limitations, and they also sometimes apprehend disability as an issue across the lifespan (see Davis 2002; Priestley 2003a; Shakespeare 2014a). Critical gerontologists argue for ceasing to separate 'the sick from the well, the very old from the less old' (Holstein and Minkler 2007:26) and for responses that acknowledge fragility and limitations (Grenier, Lloyd and Phillipson 2017). Thus, there is a need to accept that disability is part of most lives (at some point in the life span). Its social construction – in older age - has yet to be appreciated to any extent. There needs to be more recognition of the degree to which constructions of ageing and disability are intertwined, and for resistance to the framing of disability as wholly negative. Thus, it is necessary to come to terms with the similar cultural concepts and ideals that devalue disabled people of all ages.

My findings suggest that disability in later life can involve significant challenge and vulnerability – caused by individual and contextual factors - as well as loss, sadness and uncertainty. But it can also call forth resourcefulness, creativity and determination, and can occur simultaneously with the need for, and the pursuit of, a sense of purpose, efficacy, self-worth and connection – or meaning in life.

Some of the problems that disabled elders face can be ameliorated through public/community action, on the one hand, and through changes in how disability is perceived and accommodated, on the other, requiring a reorientation in general thinking about disability and about ageing. Starting to consider disability an issue for all ages and more links and bridging between the areas of disability and ageing are needed if this is to happen.

This study contributes to knowledge in being one of the few to explicate processes of finding meaning in life by older people experiencing disability. It suggests that we need to learn from their experiences.

9.6 Conclusions and Implications

A key finding of this study is that disabled older people are engaged in a dynamic process of trying to make sense of their lives through redefining and recreating a sense of meaning in life. Finding meaning in life becomes at once more important and more challenging for them following the amount of change experienced in bodies, activities and participation outlets, often accompanied by reduced family and social networks. All of this involves challenges to the sense of self, and to the sense of having a life that is meaningful. Participants' accounts suggest limitations and vulnerabilities – caused by individual and contextual factors - on the one hand, and resourcefulness, creativity and determination to have a life that makes sense on the other.

Participants expressed a desire to remake a sense of meaning in life through efforts to continue everyday activities – which often took new significance - and to participate in a range of activities, to make their own decisions, connect with others where they could, contribute to families and communities and to do things they valued doing. Thus, the third- fourth-age binary is not well marked in the minds of older disabled people who continue to identify with efforts to self-actualise, to be active and connect with others, in ways that are typically associated with the third age, and this process is essentially a meaning-making one. In this way, they assert their need to be recognised as full human beings.

The Chapter suggests the need for change in scholarship, discourse and policy. It highlights especially the need for less divisive approaches to ageing that recognise the efforts made by disabled elders to have lives they value and that they perceive as meaningful, and also the need to challenge cultural concepts and ideals that devalue impaired, disabled or ill people of all ages and to start to consider disability an issue for all ages.

Key public policy implications are that societies must find ways of integrating older disabled people in all ways of participation that are available to people of all ages.

Concluding Remarks

This is the third and final Chapter presenting and discussing findings from the inductive, grounded theory study with disabled older people, whose overarching argument is that disabled elders are engaged in a process of seeking to remake lives that make sense. Thus, this Chapter presented the third main category (responding to challenges) and brought together the discussion of the overarching conceptual category of this thesis: how, in response to unprecedented losses of functioning, activities and participation and often simultaneously of people, participants sought to continue to try and make sense of their lives and to function in ways that enabled them to perceive meaning and value in their lives.

In this Chapter and in the two previous Chapters, the arguments that I make include those ageing into disability and experiencing disability with ageing, though I have sometimes signaled that there can be differences or different emphases between the two groups. In the next Chapter, I draw out similarities and differences between the two groups.

CHAPTER 10: ‘YOU DO THINGS BACKWARDS’: COMPARING DISABILITY WITH AGEING WITH AGEING WITH DISABILITY

10.1 Introduction

Discussing with pride and delight her move at age 60 from a nursing home to an independent living apartment, Babs described a social worker saying to her - ‘you do things backwards’ – by which he meant leaving a nursing home at a stage when others were going in. This illustrates some of the inversions that could be part of the experience of participants ageing with disability (AwD). This could involve a kind of bodily ageing, or fourth age, ‘before time’, or being ‘aged’ by socio-cultural meanings or public policy responses early in life. It could also involve experiencing transitions in older age as ‘normalising’, involving re-entering the standardised lifecourse following a lifetime of exclusion from standard institutions and rites of passage.

The previous three Chapters discussed the conceptual categories I identified in the data through an inductive, grounded theory method in respect both of those experiencing disability with ageing (DwA) and experiencing ageing with disability (AwD). I argued that participants coped with disablement processes by trying to remake a sense of meaning in their lives in response to change and (often) to losses of people. The overarching conceptual category of the study was ‘Seeking to Remake Lives that Make sense’. Its three main categories were:

- Bodies Perceived (or Not Perceived) as Disabling,
- Disabling/Enabling Contexts, and
- Responding to Challenges.

(See **Figure 5.1**, **Chapter 5** for a diagram of how these categories are linked). In this Chapter I draw on the findings and discussion presented in the previous three Chapters to highlight contrasts and similarities between the experiences of the two groups (AwD and DwA). Thus, I compare their experiences to address the following research question:

- Are the social processes experienced by those experiencing disability with ageing different from those ageing with disability?

I start the Chapter by considering briefly heterogeneity in the AwD group. I also recap briefly on the literature comparing the AwD experience with the experience of disability with ageing (DwA) (from **Chapter 3**).

In the main part of this Chapter, I show that there are commonalities between the two experiences – more perhaps than have been fully recognised in research to date. I suggest that the *outcomes* both groups want for their lives are similar, and that many of the difficulties and barriers they face are similar. Both groups share aspirations for connection with others, for inclusion in the mainstream and for having lives they valued or perceived as meaningful. I point to similarities but without losing sight of the cumulative disadvantage experienced by many within the AwD group that can make later life difficult.

10.1.1 Heterogeneity in Ageing with Disability

Within disability studies, it is recognised that not all disabled people understand one another's experience (Barnes and Mercer 2006; Shakespeare 2006). And, as I have suggested already, amongst participants in this study, the AwD group was heterogeneous in a range of personal/biographical and other ways.

In common, all amongst the AwD group had experienced physical and/or sensory impairment from birth, childhood or adulthood, but before mid-life, or age 45 (and thus are characterised as experiencing ageing with disability following Verbrugge and Yang 2002; Naidoo Putnam and Spindel 2012). All were living in Ireland in the community, not residential settings. But their lifecourse trajectories were diverse. They include people experiencing stable conditions and progressive ones, and people with different timings of disability onset, people never employed and people who worked until typical retirement ages. Some had been sent away to schools/care-homes or hospitals as babies or children and experienced these as difficult experiences in which education or health was neglected. Some never participated in formal education, or education stopped upon a childhood diagnosis, and they did not go on to work outside the home. For some, these early experiences radically affected the course of their lives. Others lived more standarised lifecourse trajectories and transitions. Other relevant factors included engagement or non-engagement with disability services, the nature of services provided, and varying experiences of changing public policies over time. All of this makes comparison complex and suggests that there is much scope for further research with this group.

10.1.2 Recap from existing Literature: Comparison AwD and DwA

I briefly recap here on the discussion from **Chapter 3** of how the differences between the two experiences (DwA and AwD) are generally conceived of. Key to the research question I address here is that it is unclear whether the psychological and social processes of ageing are different for the two groups (Putnam 2002; Freedman 2014). The two experiences are often assumed to be different. This is based on the fact of different medical aetiologies and on economic and social differences. The DwA group is assumed to age having experienced social inclusion and may have more social and financial resources available for support than the AwD group. Population based studies with the AwD group are limited.

From the review of empirical studies I discussed in **Chapter 3**, I concluded that the two groups have some things in common. I highlighted common issues related to the ongoing dynamic nature of the bodily experience, how both groups engaged in strategies to maintain a sense of self, a sense of control, independence and connection, how both groups experience loss and fears for the future, and the relevance of social and contextual factors for both groups. I identified differences relating to a sense of importance attached to a ‘disability’ identity amongst the AwD group, how that group could experience ‘normalisation’ with ageing, and also some particular challenges for that group associated with engaging with mainstream older people’s services.

Very few empirical studies compare, as I do here, the experience of the AwD group with the DwA group. Exceptions are Grist’s study (2010), which looked at adaptation to physical disability from a psychological perspective, and Bulow and Svensson’s study (2013), which focused on the experience of mental health conditions.

10.2 Comparing Disability with Ageing and Ageing with Disability

I turn now to discuss similarities and differences between the DwA and AwD experiences as I interpreted them using as headings, the three key categories I identified in the dataset (bodies, contexts and responding to challenges).

10.2.1 Bodies Perceived (or Not Perceived) as Disabling

In **Chapter 7**, I described and discussed how participants understood disability, focusing on how (and whether) they perceived their bodies as disabling and the perceived consequences, including for the sense of self. The AwD group had heterogeneous experiences of bodies.

Amongst the DwA and the AwD groups, I suggested that participants told disablement narratives involving gradual ‘decline’ or unexpected ‘catastrophe’. Amongst the AwD group, there was also a further interpretation of bodies – bodies that were impaired but not ‘disabled. In **Table 10.1,** I summarise the comparison between the two groups

Gradual ‘Decline’

Participants amongst both groups (AwD and DwA) could identify with ‘decline’ narratives associated with ideas of ‘normal’ ageing and finitude. For these participants, bodies were challenging and limiting (or more limiting than formerly) even if they did not wish to be totally defined by them. ‘Decline’ over time could be perceived on top of a narrative of ‘catastrophic’ onset (such as a condition diagnosis, accident or stroke).

Obviously, a difference between the two groups was that the AwD group was dealing with worsening impairment or onset of new impairment (sometimes contrasting with earlier periods of relative stability). For several, worsening/additional impairment represented a kind of double jeopardy (Bishop and Hobson 2015) as, say, loss of hearing compounded challenges of existing conditions like visual impairment, magnifying a sense of isolation. For these AwD participants, life lived with impairment did not seem to make it easier to avoid or face further impairment or ill-health (consistent with Simcock’s (2017) argument in respect of deafblind people).

As I argued in **Chapter 7**, both groups (DwA and AwD) experienced bodily changes that could fundamentally affect their lives, challenge their sense of self, and lead to an increasing sense of uncertainty about daily life, functioning and the future. They often associated it with finitude, with a sense of not being able to control things, forced abandonment of roles, activities and participation outlets and fears of greater dependency, all of which, I suggested could amount to a sense of biographical disruption (see Bury 1982;1997), particularly as the concept has been expanded by Larsson and Jeppsson-Grassman (2012).[69] Changes could have significant consequences notwithstanding perceptions of disability onset or worsening or 'decline', being 'normal' and 'on-time'. Participants could experience reinforcement of the biographical identity of older people *and* simultaneously experience disruption of biographical identities.

However, it is also true that the degree of change was perceived relative to the individual life lived over a lifetime – and the degree of 'competences' experienced and lost. For those who had lived very confined, marginalised or difficult lives with multiple health/impairment challenges, there could be a perception of less loss than for those whose narratives tended to be more chaptered by reference to standard lifecourse transitions (like work, marriage, parenting, retirement followed by active years). Amongst some who had lived very difficult/marginalised lives, there may have been less biographical disruption occasioned by worsening impairment or health issues with ageing, and this suggests that there is more scope for contextualisation. But even participants whose lives had been marginalised – say if they had limited or no schooling, never worked or married - could still have competencies to lose. They could still fear losing the level of independence that they had and they could still try and maintain a sense of continuity with former routines. For example, Teresa (aged 87,AwD) was born with physical impairment, lived all her life in the family home, and was proud of having learned to read though she was never sent to school. Reading had been a key outlet for her, but she can no longer read because she is now visually impaired. She is also dealing with fears of greater dependency (and the prospect of a nursing home) and negative impacts of worsening impairment on relationships. But she simultaneously enjoys greater community involvement and 'normalisation' through involvement in an older people's group. She experiences both disruption and 'normalisation'. She also retains a sense of continuity by listening to audio

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[69] As discussed in previous Chapters, Larsson and Jeppsson-Grassman (2012) suggest that disruption does not have to be a single or unexpected event and that the experience can apply to the AwD group.

books obtained from the library – the first thing she raised in her interview was by reference to something she'd learned from an audio-book.

Similarly, all participants (DwA and AwD) tended to focus on what activities and outlets were still available to them and on what they could still do. They did not want to be defined by their bodies or impairments. These can be seen as efforts to cope by minimising the effects on identity (Bury 1991). Efforts to cope represent, I suggest, seeking to live lives they value and have meaning. Thus, they tended to have a sense of themselves as changed in some respects but still continuous. The reactions of both groups were often highly ambivalent - involving pragmatism and acceptance on the one hand with hopes and efforts to maintain or to improve on the other.

'Decline' and Precarity before Time

The second type of bodily experience among the AwD group involved dealing with bodies that had disabled them for a long time or 'decline' before time. Several experienced pain, fatigue or balance issues, and communicated a sense of precarity that had been theirs for a long time. Thus, there were some differences between the oldest participants (both AwD and DwA groups) and the youngest amongst the AwD group (who were the youngest people in the sample overall) in the meanings the latter made of their experiences. For the latter, bodily changes were sometimes linked to ageing, or to time advancing, but also to the progression/ worsening of conditions. Thus, they could describe an experience of 'decline' or 'deterioration', but not always use 'age' as a discursive resource. This meant that for this group (that is, the younger AwD participants), 'age' was not always available to 'buffer' the concept of self (Kelley-Moore 2010:105).

Like the participants in another empirical study, some members of the AwD group were not very old, chronologically, but they felt that their level of bodily function resembled much older people (see Jeppsson Grassman 2013:30). For example, the youngest person in my study, Liz (age 55,AwD), likened her functioning to that of her mother who was in her 80s. Their accounts suggest that an ongoing state of uncertainty that is associated with being older and impaired (Grenier 2012:177) can also apply at younger ages for disabled people. This shows that the experience of disability has some features common across the lifecourse, or that the ‘fourth age’ comes earlier to those with a long history of disability (as Bulow and Svensson (2013) found of those with long-standing mental-illness).

‘Catastrophe’

From the AwD group, those who had experienced adult-onset disability or unstable conditions from birth/childhood, had often experienced, at various stages, fundamental challenges to identities, social lives and possible greater dependence and ongoing processes of adaptation. Those who experienced adult-onset disability, especially, tended to perceive its onset as a significant turning point and had a strong sense of contrast between life before and after. But similar points of crisis and change could also punctuate the adult experience of lifelong disability. In both cases, there could have been consequences for sense of self and identity involving a broad range of areas of life like employment, parenting and relationships.

However, I also found similar experiences amongst the DwA group, as I discussed in **Chapter 7.** Unexpected or ‘catastrophic’ onset of disability was perceived in similar terms no matter when in the lifespan participants experienced it. Even experienced in one’s 80s, it could be biographically disruptive in the original Buryan sense (a single event in a life otherwise untouched by such challenges) though it could also be followed by further challenges to identity and the need for ongoing adaptation. Investment in positive ageing discourses could, I suggested, even contribute to the sense of disruption, as expectations had not been met. One difference for those who experienced onset in adulthood (or indeed significant worsening in adulthood of lifelong conditions) was that, because of its timing, the range of areas of life affected - such as early careers or parenting of young children - was often wider than for those experiencing onset first in later life (that is, the DwA group). There was a sense too of relationships being more affected for the AwD group (see below). All of this means that the experience of long-standing disability requires a particular focus in policy approaches to older age.

I argued that Bury’s concept of biographical disruption (1982, 1991) as expanded by Larsson and Jeppsson-Grassman (2012) was relevant not only to the AwD group (as Larsson and Jeppsson-Grassman showed) but also to gradual or ongoing experiences of disablement for the DwA group – it need not be conceived of as arising from a single or unexpected event. For the AwD group these events could happen over the entire lifespan, with challenges sometimes accelerating with ageing. Thus, the experiences of the AwD group is consistent with empirical studies on ageing that I reviewed in **Chapter 3,** characterising the AwD experience as involving ongoing change and adjustment across the lifecourse (see Jeppsson-Grassman 2013; Jeppsson-Grassman *et al.* 2012; Simcock 2017).

For some amongst the AwD group, standard later-life transitions like retirement often did not occur (or had occurred at a much earlier time) and this group could appear to age outside normal generational categories (Priestley 2006). However, both they and others in the AwD group could also experience more positive transitions in older age, which I will discuss in the next section, and this was so, often despite worsening impairment/conditions.

Bodies, Impaired but not Disabled

A third set of participants amongst the AwD group experienced bodies as not (or minimally) disabling – impaired, yes, but not disabling. In this respect, they were different from others within the sample other than the comparative group that was non-disabled. This group, who were all male, tended to think of retirement as the most significant transition of recent years, and in this respect identified with peers considered in the ‘third-age’ (see Weiss 1997). They could also acknowledge intrinsic disadvantages of impairment, somewhat like feminists and others who critiqued the social-model strict impairment/disability dichotomy (see Corker and French 1999:4). But their lives were organised over decades such that they experienced disability minimally on a day-to-day basis.

Unlike most other study participants, impairment seemed to be perceived as static for this group, and they had not yet experienced any (or minimal) bodily changes that they associated with ageing or the passage of time. These participants also tended to be middle-class and to have worked until standard retirement ages and they had the resources to organise their surroundings to minimise their disabling aspects. For them, thus far, there had been no biographical disruption.

Table 10. 1 Summary: Comparison (DwA vs AwD) Embodiment

Disability with Ageing	**Ageing with Disability**	
	Similarities (to DwA)	**Differences (from DwA)**
Bodies perceived as disabling		
Perceptions of ‘decline’ associated with ‘normal’ ageing and finitude used as resources to make sense of the experience. Bodily changes often experienced as gradual. Alternatively, impairment onset could be an unexpected ‘catastrophe’. ‘Decline’ could be experienced over time in addition to ‘catastrophe’.	Similar perceptions of disabling bodies and ‘decline,’ related to worsening/additional impairment in older age. Similar perceptions of ‘catastrophe’ – associated especially with adult-onset disability, but also with worsening of conditions by people experiencing disability from birth/ childhood.	**Heterogeneous group** involving different experiences. **Ageing before time** – some of the youngest study participants perceived ‘decline,’ lived with ongoing limitation and challenge at a bodily level and had had a sense of uncertainty during the course of their lives.
Consequences of disability onset/worsening		
Perceived consequences could be wide-ranging and disruptive, involving a heightened sense of precarity and losses of key activities and participation outlets.	The consequences of disability worsening/onset of new impairments were similar.	**Double Jeopardy** – For some worsening/ additional impairments on top of existing conditions could be perceived as making life especially difficult.
Not wishing to be defined by bodies and often shifting focus to what could still be done	Similar for both groups	
Bodies Perceived as Impaired but Not Disabling		
Largely absent amongst the DwA group.		Some felt that bodies did not disable them, or disabled them minimally. They identified both with being ‘disabled’ *and* with ‘third-age’ lifestyles. Associated with impairment perceived as static and minimal changes yet due to ageing.

10.2.2 Disabling/Enabling Contexts

In **Chapter 8,** I discussed how participants could be disabled or enabled by the contexts in which their lives were lived under the following headings:

1. Social/familial factors,
2. Support/care and Appliances,
3. Physical Environments and Transport, and
4. Socio-cultural meanings in Everyday Interactions.

In **Table 10.2,** I summarise the comparison between the two groups.

Social/Familial factors,

Looking at social and familial factors, there were many similarities between the AwD and DwA groups. A key finding from **Chapter 8** was that people understood their functioning as part of a relational or social unit (particularly with a spouse) rather than as an individual. Linked lives meant that changes in others' lives affected them (Elder, Johnson and Crosnoe 2003). Crucially, lives were linked in a way that impacted on how impairments and disability were understood and experienced. I showed that loss of intimates and social networks (and changes in the functioning of others) could be disabling, and particularly characteristic of disability experienced in older age, given that losses of intimates is common (especially in late older age when impairment is more likely to be experienced). This was true of both groups (AwD and DwA). Supportive relationships from carers provided through public services (or own resources for some) could compensate to an extent.

I found that participants from the AwD group were more likely to suggest that relationships had disimproved over time due to disability. I suggest that this might occur because of pressure on relationships caused by disability experienced over a long time if family members feel their lives have been negatively affected. This again signals how public policies need to have a focus on those experiencing disability for a long time.

Support/Care and Appliances

The second heading under which I discussed disabling contexts was support/care and appliances. Having access to financial resources or alternatively appropriate, supportive public provision, facilitated functioning and participation and reduced perceptions of disability. This was an area that seemed rife with inconsistency and anomaly, and there were some differences in experience between the AwD and DwA groups.

Public services played a crucial role in the lives of many participants. Public policy constructions of disability in older age resulted in variable outcomes depending on whether participants came within older people's or disability services, as the findings of **Chapter 6** suggested might be the case. However, I did not always know which home-support service (that is, disability or older people's services) participants came under – or at least participants who experienced disability onset prior to age 65, who could potentially come under either service (see **Chapter 6**) [70]. For a few within the AwD group, it was clear from the nature and level of support they reported that they were within disability services[71] though they were older than 65, the chronological boundary between the two services. Others amongst the AwD group appeared to receive similar levels of home support to the DwA group.

The positive role that public services could play was very evident amongst those amongst in AwD group who remained in disability services after age 65 (a practice that seems to operate on a discretionary basis - see **Chapter 6**) and who had also benefitted from a decongregation approach in recent disability policy intended to shift the locus of care/support from residential settings to community settings (see **Chapter 4**).

This group – small in number amongst the sample - experienced advantages *because* they benefitted from norms set by reference to the working/adult population with its emphasis on facilitation of participation in 'ordinary things in ordinary places' as a key disability policy puts it (Working Group Report (HSE) 2012). These participants valued encouraging and facilitative support from carers and input by Personal Assistants, which enabled them to take on new activities, to perceive that they could exercise autonomy and that they were more independent now than formerly. Their interpretations of life nowadays were influenced by perceptions of having

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[70] As I noted before, my attempts to clarify this with some participants were not fruitful – as people were not always sure who exactly was responsible.

[71] And in these cases, I was also aware of this due to having recruited them through the disability organisation that provided them with support at home.

been marginalised in the past and confined to residential settings. This meant that they could be ageing with a legacy of disadvantage, such as few financial or social resources.

They could have been made ‘older’ as young adults (Priestley 2003a:146) but have gone on to benefit from a ‘lowering of generational significance’ as an older disabled person (Priestley 2003a:146). These inversions were, for example, obvious in Babs’s (aged 67,AwD) narrative, who (following childhood spent in hospitals/residential settings) attended a day centre for older people in her 20s, moved to a nursing home at age 50, and moved out to an independent living apartment at age 60. As quoted at the outset of this Chapter, Babs was amused by a social worker’s comment that she does things ‘backwards’. Thus, public policy models could now help translate aspirations for a ‘third-age’ type of lifestyle, into a reality for this group. By contrast, other participants encountered older people’s services operating on the basis of a custodial and ‘maintenance’ only model.

I pointed to the paradox of participants with similar support needs, similar chronological ages, and similar aspirations for their lives (in terms of participation and activities) living very different lives due to higher levels of security, support and technologies provided in independent living complexes run by disability services. These also involved encouragement of independent functioning, decision-making and participation. I highlight these positive experiences, not because they were typical (even amongst the AwD group), but to indicate how people experiencing disability at the level of the body maximally could also have the most positive perceptions of life nowadays – provided they had appropriate supports. This is consistent with a Swedish study suggesting that policy approaches in some countries provide potential for taking an active part in social life even for those ageing with extensive physical impairment (Larsson 2013:66).

By contrast, and ironically given that reduced social networks is characteristic of older age (Settersten 2005;2006), the lack of emphasis on the social and on participation within older people’s services could leave participants within older people’s services or within ‘senior’ housing complexes, relatively unsupported. This was especially so if they also lacked social and financial resources. Some valued warm relationships with the care-workers/home-helps developed over time, but also regretted being largely unable to get out of their homes. Such community supports as were available (like accessible buses provided by local care-centres) could be a vital lifeline.

Again, ironically, for some amongst the AwD group, escaping a ‘disability’ categorisation in some respects in early life (say through experiencing impairment largely in appearance rather than functioning, to use the distinction made by Davis 1995), meant that support now came from older people’s not disability services. In fact, they might never have had contact with disability services. Now within older people services, this could mean living in a ‘senior’ housing complex, not fully accessible for a rollator or wheelchair, and thus, not capable of supporting change over time – the exact opposite of what people’s needs are as they age (for both DwA and AwD groups). For example, Tony (aged 83,AwD) living in a local authority bed-sit for seniors (rather than for ‘disabled’ people) described preparing his breakfast as involving effort and some precariousness because his kitchen is too narrow to take his rollator – he has to grasp the counter top with one hand to try and keep himself up while using his other hand for everything else. Tony also knew that his bedsit is not suitable for a wheelchair and he anticipated that he would have to move to a nursing home if his mobility continued to disimprove. This approach to senior housing reflects a bureaucratic approach in which the status of disability is ‘frozen’’ (Rickli 2016:126-7) in which older disabled people are categorised as ‘elderly’ not ‘disabled’ (Jönson and Larsson 2009).

Overall, the study’s findings suggest many anomalies in the provision of support and services. The administrative distinction based on chronological age (of 65) contributes to inconsistencies as applied to the complex category of disability as it interleaves over the span of a life. However, it is also clear that there were advantages – perceived in terms of the balance between security and support of choice-making and encouragement and support for participation - provided to some within disability services *because* they benefitted from norms set by reference to the working/adult population. One implication is that these approaches could also benefit other participants from both the AwD and DwA groups if they were they available to them.

Physical Environments and Transport

Discussing home, external environments and transport, I concluded that both AwD and DwA participants took accessible homes and environments for granted if they had them (perceiving themselves less disabled as a result). Environments that involved barriers for disabled people generally were also disabling of disabled older people - both AwD and DwA groups. One difference, and a paradoxical one, given how they are not generally considered ‘disabled, was that the DwA group was *more* likely to stress difficulties encountered in physical environments like undipped footpaths, inaccessible transport or cultural spaces that lacked hearing technology. This is presumably because such issues were a relatively recent problem for them.

Members of the AwD group did discuss disabling environments – this was especially so if they depended on public services and lacked resources for taxis or were waiting for adaptations to homes. But overall these issues seemed more in the background for the AwD group. There was a sense in which having had decades of bodily limitations and/or disablism in everyday encounters or whole lifecourse trajectories strongly marked by how disability was constructed and ‘managed’ in society (Irwin 2001), they had long since come to accept that these issues exist (though not the justice of them) and that they must live their lives as well as they could despite them.

Socio-cultural meanings in Everyday Interactions

The two groups experienced differences due to socio-cultural meanings made of impairment, ageing and the lifecourse. This is the area where contrasts between them are most striking. While the DwA group could experience othering with onset of impairment, the AwD group could experience ‘normalisation’ with ageing in aspects of life. Discrediting experienced by the DwA group and the ‘normalisation’ by the AwD group occur as part of larger societal and cultural processes in which constructions of ageing and of disability are intertwined as is the social devaluation of each.

‘Normalisation’ involved an element of re-entering the standardised lifecourse for the AwD group (Grenier, Griffin and McGrath 2016:19), as physical appearance or lives came to resemble those of their age peers. It was associated with visible impairments being perceived as less visible, with needing care/support becoming more ‘normal’, and with people who had lived lives that were confined or marginalised finding new ways to participate in communities, sometimes with groups of older people (and often due to public or community provision).

Thus, social constructions of age and the lifecourse affect meanings made of disability (Kelley-Moore 2010). A process of ‘normalisation’ for the AwD group is consistent with experiences reported in other studies and discussed in **Chapter 3** (see Jeppsson Grassman 2013:31; Bishop and Hobson 2015; Pollington 2008:33, cited in Simcock 2017). It is worth stressing that these positive changes were experienced by participants from the AwD group who could simultaneously experience bodies that increasingly disabled them and they could also experience fears and uncertainty about the future. Thus, bodies might make life more precarious and difficult, but simultaneously life was less difficult in other ways: there could be both a ‘double jeopardy’ *and* an element of ‘normalisation’. There could be both a sense of biographical disruption (especially associated with the prospect of increasing dependence) and ‘normalisation’ of aspects of life at the same time. An example of this came from Helen (aged 68,AwD) who described how life was worse in some ways (due to increased impairment and fears of greater dependency) but better in other ways (because being older made her appearance less notable and helped her to resist others’ judgements).

A different – and inverse – process was experienced by some of the DwA group who could perceive rejection in everyday interactions, which they associated with disability onset, especially with starting to use aids/appliances as well as exclusion/marginalisation from inaccessible environments. They could perceive that they had been put in a discredited social category, and they could also resist this and try to work around it. Thus, the social construction of disability (that is, as discredited or not conforming to the ‘normal’) frames the meaning and experience of ageing and the lifecourse (Kelley-Moore 2010). I suggest that this too could threaten one’s sense of having a valued self and be part of a sense of rupture or disruption. This is a striking finding, given how impairment is often considered a social norm of ageing.

Thus, what DwA participants experienced in daily interactions was consistent with how disabilty scholars discuss the experience of marginalisation or exclusion from the mainstream of social interaction that is the experience of disabled people generally (see Watson 2003: 40). A tendency not to consider the DwA group as 'disabled' does not protect them from disablism[72]. I argued that participants might actually opt for a 'decline' ideology (Gullette 2004;2010) - 'accepting' that their age made it time to stop doing things. This could help deal with the hurt experienced when faced with disablism, thus, buffering one's self-concept. It highlights how the withdrawal associated with the 'fourth age' is partially socially constructed.

This brings me to the issue of a 'disabled' identity. Here I found some differences, but also some similarities between the two groups. The DwA group suggested that what they experienced was 'normal' for their age and not 'disability', which they associated with not being able to do anything. But even amongst the DwA group, those who attended a centre run by a disability organisation[73] or who were involved in a condition-specific organisation (such as for lip-reading) could have a political and analytical approach to disability and an orientation towards activism as well as a sense of belonging (if not an identification with 'disability' in all cases).

For disabled people generally, contact with other disabled people, and enabling them to take a positive approach, can improve lives (Wendell 1996:27; Shakespeare 2014a:82). This underlines how activism, identification and belonging can flow from policy/activist approaches and that the schism in policies between disability and ageing contributes to the DwA group (who often only encounter older people's frameworks) in general identifying only with medical-model approaches.

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[72] Miller *et al*. 2004:9: **Disablism** is 'discriminatory, oppressive or exclusionary behaviour arising from the belief that disabled people are inferior to others.'

[73] In **Chapter 5'**s outline of methods, I explained that this happened for two reasons: (1) some had experienced disability onset after midlife but before age 65 - DwA includes those who experienced mid- or late-life onset (Verbrugge and Yang 2002) (2) others were attending a disability centre (that is, run by a mainstream disability organisation) that (very unusually in an Irish context) specifically targeted clients experiencing disability for the first time in later life.

Furthermore, DwA participants not identifying with a ‘disability’ identity or with disability activism could resist prejudice or disablism of others (without framing it in those terms) in ways very similar to voices from movements of disabled people (see Watson 2003; also Grenier 2005). For example, they could resist attempts to depersonalise them or exclude them from activities.

Maintaining a strong sense of a ‘disability’ identity was a feature that distinguished the AwD experience from the DwA experience in some empirical studies I reviewed in **Chapter 3** (see Jeppsson-Grassman *et al*. 2012; Cooper and Bigby 2014). I found that the AwD group was more likely to use terms like ‘disability’ of themselves, and some described ‘disability’ as encompassing social/environmental barriers, and they often also recalled positive aspects of their life associated with disability organisations or activism. However, my findings are different in that most of the AwD participants did not stress their ‘disabled’ identities. Rather they stressed their experiences as ‘normal’.

This may be because I did not specifically target activists (unlike some of the studies reviewed; see Holme 2013) nor was I a disability activist myself (unlike pioneering writers such as Zarb and Oliver 1993). Or it may reflect something about my sample – the AwD group was predominantly female – or the nature of disability activism in Ireland. Whatever the reason, I found that the AwD group could have a complex relationship to the identity ‘disabled’. However, this is consistent with some studies with younger disabled people who preferred to think of themselves as part of the mainstream (see Priestley *et al.* 1999; Watson 2002; Shakespeare 2014a) and with how AwD participants in an empirical study reviewed in **Chapter 3** (Raymond, Grenier and Hanley 2014) stressed how they had lived an ‘ordinary’ life.

Thus, all participants wished not to be seen as an outsider or as different. They wanted to be seen as ‘normal’ or as a ‘full human being’ (Morris 2006:10). Implicit in this is a rejection of the idea of an exclusive ‘normality’ (Davis 2013b; Shakespeare 2014a:99). Instead, they communicated a sense that there is more to them than any label, a desire to continue to live mainstream lives they perceived as connected to others, and, as I argue, as meaningful.

Table 10. 2 Summary: Comparison (DwA vs AwD) Disabling Contexts

Disability with Ageing	Ageing with Disability	
	Similarities (to DwA)	**Differences (from DwA)**
Social/Familial Factors		
Presence of intimates could reduce experiences of disability. Those with smallest networks experienced disability maximally.	Experiences were similar.	Some of the AwD group, especially, perceived that relationships had changed and become less supportive over time due to long-term disability.
Support/care, Therapies and Appliances		
Having access to financial resources or supportive public provision reduced disability and facilitated functioning. Valued longstanding relationships with professional carers. Care could also be experienced as inflexible/disabling.	Experiences were similar.	A small number of those who had continued within disability services after age 65 valued a model of care (with norms set by reference to the working/adult population) that facilitated choice-making and participation.
Home, External Environments and Transport		
Functioning and participation understood in terms of how homes and environments facilitated functioning. Extrinsic barriers stressed.	Experiences were similar.	Extrinsic barriers stressed less, as they had been a feature of life for longer. Still stressed by those with least resources who most relied on public provision.
Socio-cultural meanings made of impairment		
Perceptions of othering: experiences of marginalisation and exclusion, associated especially with starting to use aids/appliances.		Perceptions of 'normalisation' with ageing of aspects of life.
Most did not use terms like 'disability' or identify as 'disabled', perceiving functioning as 'normal' for their age. Some *did* identify with disability activism, or resisted disablist attitudes without identifying with disability activism. None wished to be different, or as part of a discredited category.	Similar rejection of discrediting labels and wish to be part of the mainstream even if they identified as 'disabled' or had been involved in activism.	More likely to use terms like 'disability', sometimes understood disability as broader than impairment, and could have positive associations with disability organisations.

10.2.3 Responding to Challenges

In **Chapter 9**, I outlined the third main category of this thesis and discussed the overarching conceptual category – seeking to remake lives that make sense. I argued that in response to the twin challenges of disablement (onset or worsening) and reduced social networks, participants sought to remake their lives so as to perceive them as meaningful. Under this heading, there were more similarities than differences between the two groups (AwD and DwA). See **Table 10.3,** where I summarise the comparison.

This involved a process of responding to uncertainty and changes in bodies and functioning (involving additional impairments or worsening in conditions for the AwD group), losses of activities and participation outlets (due to personal and contextual factors), and often simultaneously losses of people. A cycle of losses could reduce a sense of life as meaningful (see Baumeister 1991; Holstein 2015). I showed how, in their responses participants were seeking to continue to make sense of their lives and to function in ways that enabled them to perceive their lives as meaningful[74]. This becomes simultaneously more important and more challenging for them.

Thus, both groups expressed the need for a meaningful life through efforts to minimise the effects on identity of disablement processes, to resist othering or exclusion, to continue everyday activities (which they could invest with new meaning), to participate in a range of activities, make their own decisions, connect with others, and to contribute to families and communities, where they could.

Both groups (DwA and AwD) could identify with qualities associated with third age and similar discourses of ‘successful’ or active ageing even if they did not fit standard criteria. Specifically, they could identify with goals of self-development, activity and social connectedness typically associated with these discourses. This was, I suggested, because they were seeking

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[74] I discussed this using Baumeister’s (1991) four ‘needs’ for meaning (purpose, efficacy, self-worth and moral-worth), along with the addition of the need for connection or belonging (from Stillman and Baumeister 2009; Derkx 2013; Baars and Phillipson 2014).

to perceive meaning in their lives, and because their identities are not just based on their bodies or impairments. Binary third-and fourth- age notions are further problematised by my findings (discussed above) suggesting that some AwD participants had perceived precariousness and ‘decline’, usually associated with the fourth age, for decades.

One of the threats to a sense of coherence or meaning in life for the DwA group could be a sense of having entered a discredited social category – something they often resisted and tried to work around. What was different for the AwD group was that perceptions of ‘normalisation’ could help with a sense that life now made sense or had value. Some took action to get involved in communities of older people. Some had also perhaps gained a sense of validation or self-worth and moral-worth or efficacy - associated with a sense of meaning in life (Baumeister 1991) - from finding that they could now conform to values of autonomy and independence, associated with being fully adult – or they perceived that needing some support was now the norm not only for them but for their chronological peers.

Having a sense of greater autonomy now was expressed especially by those who had shifted to living in community (after residential care) with support from public services, which were crucial to perceptions of life as positive, both connected to community and ‘independent’ now. Whole lives might have been characterised by physical segregation from family and work, reinforcing perceptions of cultural difference (Finkelstein 1991). One of the things that they appreciated about the present is being able to distance themselves from ‘discourses of dependency and otherness’ (Priestley 2006:139). It helped them perceive that lives were meaningful now and the support they received facilitated this. Heterogeneity within the AwD group suggests the need for further contextualisation.

Table 10. 3 Summary: Comparison (DwA vs AwD) Responding to Challenges

Disability with Ageing	Ageing with Disability	
	Similarities (to DwA)	**Differences (from DwA)**
Disabled older people can engage in a challenging process of remaking lives that make sense, involving investing everyday activities with new meaning, trying to maintain existing occupations and connections and to find new ones to compensate for losses.	Similar for both Groups	Some could experience 'normalisation' of aspects of life - processes that contributed to a sense of life as meaningful.
Continued to identify with the need for engagement, self-development and connection typically associated with the 'third age'. Their accounts problematise the third- fourth- age binary.	Similar for both Groups	

10.3 Discussion

In this Chapter, I summarised key findings of this study and compared the experiences of the two groups – disability with ageing (DwA) and ageing with disability (AwD) - under three headings: bodies, contexts and responding to challenges. These are the three main categories that I identified in the data from interviews with older people following an inductive process of analysis (see **Chapters 7-9**).

In doing so, I address the research question of whether the social processes experienced by those experiencing disability with ageing were different from those ageing with disability. As I set out at the outset of this Chapter, the background involves suggestions that the social processes of ageing may be different for the two groups, informed by the fact that there are different aetiologies associated with disability onset in early and late-life, and that the AwD group can age with cumulative bodily, economic and social disadvantages.

I found that, while the AwD group, especially, had heterogeneous experiences (suggesting the need for more research with this group), there were many similarities between the two groups (DwA and AwD) as well as some differences. Both groups could perceive themselves as disabled by their bodies and their contexts. Bodies *and* society could be disabling (Shakespeare 2014a).

To summarise **difference**s first, the key area was in socio-cultural meanings made of ageing and of disability. The AwD group could experience 'normalisation' as aspects of lives came to resemble their chronological peers more, while the DwA group could experience discrediting or othering, which they often associated with starting to use aids/appliances. Thus, social constructions of age and the lifecourse affect meanings made of disability, and, conversely, social constructions of disability frame the meaning of ageing and the lifecourse. The latter means that becoming impaired could be perceived as being discredited or not conforming to what is considered 'normal' at whatever age it happened. In response to changes that come with ageing and disability (or worsening disability), members of both groups engage in processes of trying to remake their lives so as to have a sense of meaning in life. In this endeavour, the AwD group could be helped by 'normalisation' processes, while the DwA group could be hindered by 'discrediting' processes.

Both 'normalisation' and discrediting occur due to meanings made of disability, and within larger societal and cultural processes in which the social devaluation of disability and ageing are intertwined. As I have argued already, fears and denial of the realities of vulnerability in society at large can negatively affect disabled people of all ages. This highlights the need to challenge cultural concepts and ideals that devalue disabled people no matter at what age they experience impairment.

I found a nuanced rather than binary approach to the issue of a '**disability' identity**, as between the two groups. The AwD group was more likely to use the term 'disabled' of themselves, but neither group wished to be seen as an outsider, as different, or as part of a discredited category, preferring to be seen as part of the mainstream and 'normal'.

Taking **similarities** - amongst both groups were people experiencing **bodies** that significantly disabled them or caused them suffering. Bodies could cause life to be permanently uncertain and reduce the activities available. Uncertainty or precarity could be the experience of some of the AwD group over the course of their whole lives. But neither group wished to be defined by their bodies. Both groups stressed what they could still do rather than what they could not do. The accounts of both groups suggest experiences of limitations, vulnerabilities and uncertainty, on the one hand, and resourcefulness, creativity and determination, on the other.

Physical home/community environments that tend to disable people with impairments generally were also disabling of both groups. My findings support Wendell's argument (1996:18-19) that reduced opportunities experienced by disabled elders are no more attributable to 'nature' than those experienced by non-elderly disabled people. I found that disabling physical environments (like public transport) could be *more* stressed by the DwA group because, presumably, they had only been encountered as barriers in more recent times. Barriers in the physical environment are not a new phenomenon for the AwD group and lack of social and material resources continued to exacerbate the problems for some.

For both groups, lives with a lot of **social support** meant that experiences of disability could be reduced (especially by presence of spouses). Alternatively, reduced and reducing family and social circles could increase experiences of disability, and this is a distinguishing feature, I suggest, of the experience of disability in older age. Participants from the AwD group were the ones who were more likely to suggest that relationships had disimproved over time due to disability.

Having access to financial resources or alternatively appropriate, **supportive public provision of support/care and appliances**, could facilitate functioning and participation and reduce experiences of disability for both groups. Some participants among the AwD group who remained in disability services after age 65 experienced advantages *because* they benefitted from policy norms set by reference to the working/adult population – they valued having security while also being facilitated to exercise choice and to participate in communities. An implication is that public policies on ageing would serve disabled older people better if (like disability services – at least as experienced in some cases) they also emphasised support for the exercise of choice, and support for community participation.

At a most fundamental level, both groups **share the same aspirations for their lives –** for connection with others, for inclusion in the mainstream and for having lives they valued or perceived as meaningful. Both groups can engage in a dynamic process of trying to recreate meaningful structures for their lives in response to loss and change, or of trying to remake their lives in ways that make sense – a process that follows from the amount of change experienced in bodies, activities, ways of participating, and amongst intimates and social networks. Thus, they try to maintain and develop a sense of purpose, self-worth, moral-worth and self-efficacy (or to fulfill Baumeister's (1991) 'needs' for meaning) and also of a sense of connection (also essential to meaning in life, see Derkx 2013; Baars and Phillipson 2014). In short, they seek to live lives they value and that have meaning for them.

In seeking to do so, both groups could identify with qualities associated with models of 'successful ageing', active ageing or 'third-age' (such as the emphasis on engagement, self-development and connection with others), even if they did not fit standard criteria. Thus, accounts of both groups challenge the third- fourth- age binary. An implication that it is yet to be fully appreciated is that many older disabled people (DwA and AwD) are seeking opportunities not just to pass time but also to perceive meaning in life.

Responding to the research question (above), these findings suggest that, while there are differences in their experiences, the *outcomes* both groups want for their lives are similar, and that many of the difficulties and barriers they face are similar. Barriers could include inaccessible physical environments, discrediting attitudes of others (especially stressed by the DwA group but part of life for longer for the AwD group), losses of intimates and lack of material resources or supportive public services. These findings support Townsend's (1981b:93) argument, outlined in the

Introduction to this study, for a focus on the *outcome* of limitation rather than on the individual or biological. Consequently, I wonder if biomedical determinations of different aetiologies (between early and late onset of disability) has led to assumptions of more difference in social experiences of the two groups than is the case.

Suggesting that the two experiences share some things in common is compatible with what I have argued already in respect of public policy approaches to the AwD group – that there must be a particular focus within public policies on them, as cumulative disadvantages (in functioning, in health, in access to education and employment, and in other ways) experienced over their life spans requires this. But this, I suggest, may also be true of anyone experiencing disability over the long-term, irrespective of the timing of its onset. Members of the AwD group are not the only ones to experience cumulative disadvantage. Some participants within the DwA group also had limited resources (social and financial) in older age that left them also with difficulty in continuing to live lives they valued.

Overall, I conclude that there are many similarities in the two experiences. Many of the differences arise from sociocultural meanings made of impairment. These arise as part of a larger societal tendency to valorise independent adulthood and consequently to devalue other social categories. Thus, as Baars (2010:115) suggests, denial of the realities of vulnerability in society at large can damage disabled people of all ages.

This study contributes to knowledge, as there are almost no studies that address the experience of disability across the two groups (DwA and AwD) or that compare their experience as this study does.

10.4 Conclusions and Implications

I conclude that there are commonalities between the two experiences – more than have been fully recognised in research to date. I do so without losing sight of the cumulative disadvantage experienced by many within the AwD group that can make later life difficult, and which means that public policies must develop a particular focus for this group. However, cumulative disadvantage can also be experienced by some within the DwA group.

This study suggests that both groups want similar outcomes for their lives and that they face many similar difficulties and barriers. Both groups seek connection with others and to have lives they valued or perceived as meaningful. Differences between the two groups arise from sociocultural meanings made of impairment at different points of the lifespan. These arise out of societal fears of realities of human vulnerability (and a related tendency to deny them), which affects disabled people of all ages.

Given that both groups share aspirations to live self-actualising lives, a key implication for public policies and for community organising is the need to find ways of including all disabled older people in active ageing frameworks and, indeed, in all opportunities for participation.

Concluding Remarks

In this Chapter I compared the experience of the DwA group to that of the AwD group. In the next, and final, Chapter of this study I summarise the conclusions of the study overall and its recommendations for scholarship and public policy.

CHAPTER 11: CONCLUSIONS AND RECOMMENDATIONS

> ‘Disability asks us to consider what we value in life’
> (Goodley 2014:xi)

This chapter draws the thesis to a close. I first revisit the rationale for the study, its placing within gerontology, and its research questions presented in **Chapter 1**, and I summarise its key findings. All doctoral theses seek to contribute to knowledge. Therefore, I suggest how this study speaks to the academic literature and suggest how it makes an original contribution to gerontology – most notably, in relation to how disability is experienced and conceptualised, in relation to the subjective impact of onset (or worsening) of impairment in older age, and in relation to processes of creating meaning in life by those experiencing disability in older age.

As well as addressing the study’s contribution to scholarship and making some recommendations for further study, I draw together some of the contributions to and implications for policy-making that have been suggested throughout the study and I make some policy recommendations. Possible limitations of this study have already been conceded in **Chapter 5**. I finish with a few concluding remarks.

11.1 Rationale for the Study and its Approach

I introduced this study by highlighting a series of paradoxes as to how policy and activism, theorising and conceptualisation are approached in the areas of disability and ageing. Thus, despite impairment being considered a social norm of ageing, older people with impairments are rarely regarded as ‘disabled’ (Priestley 2002; 2006). I also pointed to the fact that it remains unclear if the social processes involved for those ageing with disability (AwD) are different from those involved for those who first experience disability in older age (DwA) (Putnam 2002; Freedman 2014).

I reviewed separate models or conceptualisations of disability in **Chapter 2,** and, in **Chapter 4**, I reported on the separate approaches of public policies on ageing and on disability. I suggested that in Ireland overarching public policies do not now, to any extent, articulate values, aims or intended outcomes of services/supports, or indeed of society, for disabled older people (either for the DwA or AwD groups).

My review of the academic literature and empirical studies (**Chapter 3**) confirmed the point I made at the outset that there is little theorising that addresses ageing and disability together, but largely separate approaches to ageing and to disability. It also confirmed the need for more empirical work on the experience of being older and disabled. Thus, knowledge of the so-called ‘fourth age’ or of disability and ageing from the perspective of older people is still under-developed from a sociological perspective, and the meanings made of the transitions involved are not well understood within lifecourse studies (see Grenier 2012:169-182; Jeppsson-Grassman *et al* 2012). Least of all is known about the experience of those ageing with disability (AwD).

Consistent with a constructivist approach to the lifecourse (Holstein and Gubrium 2000:41), the study sought to understand how experience is made meaningful in relation to the passage of time. Thus, it is informed by a social constructionist approach to the lifecourse and by critical gerontology. To look at disability and ageing together, two subjects usually apprehended separately, is consistent with the commitment of critical gerontology to provide evidence to challenge assumptions and beliefs about ageing and to highlight experiences of disadvantage and difference (see Bernard and Scharf 2007). This study’s focus on how institutions and policies shape lives and categories of people aligns with the emphasis on structures in a political economy approach within critical gerontology. Its emphasis on subjective processes of meaning-making by older people within a wider context means that this study is placed especially within the moral economy or cultural strand of critical gerontology.

11.2 Recap: Objectives and Research Questions

This study aimed to explore the subjective experiences (and meanings made of those experiences) of people who can be categorised as in the DwA group and those in the AwD group as well as including (for comparative purposes) a small number of older people not experiencing disability. It involved a constructivist grounded theory method and used a biographical narrative approach. Thus, the main focus was on two groups whose experiences are not well understood, but who are assumed to be very different to each other, though very few studies compare them. It also explored the separate organisation of public policies on ageing and on disability and the consequences for the two groups and explored this with people working on social care in Ireland either in disability or ageing.

I recap the research questions here:

- How do older people experience disablement processes and what meanings do they make of those experiences?
- How do disabled older people respond to the challenges involved?
- Are the social processes experienced by those experiencing disability with ageing different from those ageing with disability?

The first was explored mainly in **Chapters 7** and **8**, the second mainly in **Chapter 9** and I drew together findings relative to the third in **Chapter 10**.

The motivation for carrying out interviews with policy-makers, service-providers and representative groups was in part to try and understand how the chronological boundary (of age 65) between disability and older people's services works in practice. The following were the research questions:

- How does the chronological boundary of age 65 operate between services for disabled people and older people in practice?
- How do people working in these fields relate to this separate organisation of services? and
- What are the implications for disabled older people?

I reported my findings on this in **Chapter 6**.

11.3 Findings Summary

The key finding of this study can be summed up in one sentence:

> Older people experience disablement in their bodies and in their contexts, which challenges their sense of meaning in life (often in combination with losses of intimates), and they respond by engaging in challenging processes of trying to remake lives they perceive as meaningful.

Thus, the findings show how disablement processes were experienced by older people and how they responded. They show how the experiences of the DwA and AwD groups compared with each other. And they also point to some of the anomalies in the organisation of public services at present and what some of the challenges to greater integration of disability and older people's services might be.

By focusing on how disabled elders interpreted change and reacted to it, the findings challenge some of the assumptions or informing paradigms of the academic fields that I engaged with. Specifically, it challenges normative notions about the nature of the lifecourse, especially about the residual nature of the so-called fourth age and of the presumed division between third and fourth ages. It challenges overwhelmingly biological explanations of impairment in older age that dominate gerontology, and it challenges the tendency within disability studies not to engage with disability experienced in older age.

11.3.1 Findings: Processes of disablement: DwA and AwD

Disabled older participants experienced disablement both at a bodily level *and* in interactions with contexts (including support and relationships, physical environments, attitudes, services and resources). Bodies *and* society could be disabling.

I showed that the perception of bodies that now ‘limited’ them (or limited them more than previously) was a central part of the experience for most. However, they did not define themselves by their bodies, or want to be defined by them, and they focused on what they could still do. I showed that participants also experienced disability arising from barriers that affect all disabled people such as prejudice of others and inaccessible environments, and that losses of intimates, particularly common in older age, can contribute to experiences of greater disablement. Those who lack social and financial resources could experience disability maximally.

They perceived resulting uncertainty about daily life and the future, were forced to abandon activities and participation outlets, and they could experience a high degree of loss, suffering and fears of greater dependency. I showed how this, as well as perceptions amongst the DwA group of being consigned to a discredited category, amounts to a fundamental re-thinking of biography and self-concept, even when disablement occurs at a stage in life when participants consider impairment as ‘normal’ or ‘on-time’.

Thus, they experienced disablement in ways that were broader than the biological processes that dominate explanations of impairment in older age. Biomedical explanations omit significant parts of the experience and overlook the fact that some of the challenges are amenable to social change. Instead, my findings show that a biopsychosocial understanding of disability – where disability is said to arise from the interaction of individual conditions with contextual factors - accords with the experiences of participants in this study.

11.3.2 Findings: Responding to Challenges: DwA and AwD

I showed how participants responded to the twin challenges of disablement (or worsening disability) and loss of intimates and social networks (due to deaths or illness/impairment of others). Both could reduce perceptions of life as meaningful and, in combination, were particularly challenging. Thus, these changes forced change in how participants perceived meaning in their lives.

They responded through a process of trying to cope and to remake their lives so as to perceive them as meaningful. This is the overarching finding of this study and I characterise this process as seeking to remake lives that make sense. The study evidences engagement in challenging and ongoing processes of coping with, and responding to, the challenges of disablement. Their actions included investing everyday activities with new meaning (as they were threatened), maintaining participation outlets and connections with others where they could, and sometimes seeking to take on new activities and make new connections. Some succeeded in making positive change and this was often helped by community or public organising or services.

That they are engaged in such processes represents a challenge to assumptions about the residual nature of the so-called ‘fourth-age’ that underpins mainstream sociological approaches to ageing and the lifecourse. It also represents a challenge to societal responses to disabled elders, specifically narrowly-focused policy and community responses that ignore the full range of their needs and aspirations for meaningful lives.

11.3.3 Findings: Social Processes of the two groups – DwA and AwD - Compared

Comparing the two groups, I found that, while the AwD group, especially, had heterogeneous experiences, there were similarities in the two experiences. Both groups wanted similar *outcomes* for their lives. They faced many similar difficulties and barriers. At a most fundamental level, both groups share aspirations that include connection with others, inclusion in the mainstream and for having lives they valued or perceived as meaningful.

Key differences between the two groups arise from sociocultural meanings made of impairment at different stages of the lifespan – with the DWA group experiencing impairment onset as a discrediting process, while the AwD group could experience ageing as ‘normalising’ in some respects (from the perspective of a lifetime of othering and marginalisation). This occurs as part of larger societal and cultural processes in which constructions of ageing and of disability, and the social devaluation of each, are intertwined.

I conclude that there are more commonalities between the two experiences than assumptions to date suggest. I do so without losing sight of the cumulative disadvantage experienced by many within the AwD group that can make later life especially difficult and suggest that this can be true of all those who experiences disability for a long time irrespective of the timing of onset.

This finding highlights a challenge (implicit in all the study’s findings) to the extent of division between scholarship in the fields of ageing and disability. It points, at the least, to the need for scholarship on ageing to engage more with scholarship on disability and vice versa.

11.3.4 Findings on Policy and Practice

My interviews with policy-makers and others working on ageing and disability in Ireland confirmed that the medical model still dominates social care for older people in Ireland, meaning, amongst other things, that older people’s services place less emphasis on social/community participation and user-direction than do disability services. I showed how the separate frameworks for policy on ageing and disability contribute to keeping in place medicalised, reductionist notions about the nature of disability in older age, by suggesting that one is either ‘disabled’ or ‘older’ not both. This is connected with, and reinforced by, the lack of a concept of disability first experienced in older age (with disabled older people often thought of as ‘just elderly’). The investment of staff in age-segmented frameworks points to some of the challenges inherent in any attempts at integration between disability and older people’s services.

This affects disabled older people by influencing how services for them are conceived of. It also influences how older people view themselves, given that public policies provide narratives that affect the public legitimacy and personal identities.

Older people are also affected by anomalies that I found operating in practice. A small difference in the timing of disability-onset around one’s 65th birthday can determine engagement with a different service model thereafter. And at the chronological boundary of age 65, some within the AwD group appear to remain in disability services, while others transition to older people’s services, which could involve a diminution in the level of services.

11.4 The Study’s Empirical and Theoretical Contributions

As I indicated already, by focusing on how disabled elders interpreted change and reacted to it, this study makes an original contribution to gerontology. It evidences how disability is experienced in older age, it explores subjective impacts of onset (or worsening) of impairment in older age, and it shows how disabled elders engage in processes of creating and recreating a sense of meaning in life. The study also adds to knowledge about the subjective experience of the so-called fourth age and responds to calls for more bridging research between the fields of ageing and disability.

First, I showed how older people experience disability and interpreted this through models of disability, rather than taking a biomedical standpoint. Gerontologists increasingly draw attention to social causation of disability (see Kelley-Moore 2010; Henning-Smith 2016), and a biopsychosocial model of disability is considered useful in attempts to bridge the fields of disability and ageing (see Naidoo, Putnam, and Spindel 2012). But this study makes explicit, though an inductive process, how the subjective experience of disability in older age corresponds with a biopsychosocial model of disability, and, thus, to a model, originating in medical sociology and applied largely within the field of disability but not of ageing. In doing so, it challenges paradigmatic assumptions about ageing and it opens up the potential for more conversations and greater bridging between the two fields.

Second, the study makes a contribution to theorising in the sociology of chronic illness, specifically to the concept, originally from Bury (1982, 1991), of biographical disruption. Theorising on ageing within this field is considered underdeveloped. The study responds to the call from Williams (2000:61) to extend the biographical focus of studies from the middle years of life, and to Larsson and Jeppsson-Grassman's (2012) application of biographical disruption to the AwD experience, and their call for more refined contextualisation. It is the first empirical study (so far as I am aware) to apply the notion of biographical disruption to both groups (DwA and AwD). It amounts to an empirical testing of the notion in this context. It contributes by showing how the concept of disruption is relevant to both groups (DwA and AwD), and it in turn expands the notion as developed by Larsson and Jeppsson-Grassman (2012), who applied it to the AwD group. I suggest that their version also fits the experience of disablement in older age (that is, DwA group).

The study also contextualises the conception of biographical disruption by evidencing a broad range of factors that could contribute to this experience in older age. It thus extends the work of scholars who have focused on one or other group (DwA or AwD) or on specific illnesses/conditions.

Third, the study makes a contribution to theorising meaning in life. This builds on Bury's (1991:461) suggestion that coping with chronic illness involves efforts to maintain a sense of value and meaning in life. It does so by exploring how older disabled people respond to disablement (and worsening disability) drawing on Baumeister's (1991) framework (or ‘needs’) for meaning in life. It amounts to an empirical application of Baumeister’s framework of meaning in life to the situation of disabled elders - the first, again so far as I am aware. It adapts Baumeister’s framework, adding the need for connection or interdependence as part of the meaning framework[75] (see Derkx 2013; Baars and Phillipson 2014).

It builds on the discussion of the application of Baumeister’s framework to older age from Baars and Phillipson (2014) and applies the framework to older people experiencing disability. Specifically, it evidences how meaning in life becomes simultaneously more important and more challenging for disabled elders and how they respond to the twin challenges of disablement (or worsening disability) and losses amongst intimates and social networks. It extends Baumeister’s framework by showing how the ‘needs’ for meaning can be experienced and interpreted by disabled older people. For example, it shows how they can invest the activities that are still open to them with new meaning, and evidences how even very old people experience and try to meet the need for a sense of purpose (which is understood by Baumeister as involving future-orientation or inner fulfilment).

Fourth, the finding that disabled older people are engaged in continuously trying to maintain and remake a sense of meaning in life challenges assumptions about the residual nature of the so-called ‘fourth-age’ that underpin mainstream gerontological approaches to ageing and the lifecourse. It suggests that transitions of older age associated with impairment require ongoing processes of interpretation and reinterpretation. Thus, the study can be said to make a contribution to the literature on the fourth age by helping to develop a better understanding of people’s experiences. It also challenges the very premise of the ‘fourth age’ by showing how contextual factors, such as environmental barriers and disablist reactions to impairment, are a key component in its construction as a time of withdrawal and stepping back, and by showing how the third-age/fourth-age binary is not well marked in the minds of older disabled

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[75] Although, as I made clear already, even though Baumeister does not list connection of belonging amongst the four ‘needs‘ for meaning, he nonetheless sees the need to belong as a most basic human need and a motive for meaning-making (Baumeister 2005; Stillman and Baumeister 2009; Baumeister, Maranges and Vohs 2017).

people. Instead, they continue to identify with efforts to self-actualise, be active and connect with others in a process that is essentially an effort to have lives of value and meaning. It points to the need for the development of counter-narratives on ageing that are inclusive of the experience of disability in older age.

Fifth, the study makes an empirical contribution by comparing the experience of physical and sensory disability across the two groups (DwA and AwD), as there are almost no studies that do so from a sociological perspective. Showing that the outcomes that both groups want for their lives are similar and that many of the barriers faced are similar, it challenges assumptions amongst scholars that the two experiences are very different, while also acknowledging heterogeneity, particularly within the AwD experience, requiring more contextualisation. This challenges the extent of the divisions between the fields of scholarship on ageing and disability and suggests the need for scholarship within each field to engage more with scholarship from the other.

Finally, the study contributes to an emerging body of knowledge about the barriers to bridging initiatives between the policy fields of disability and ageing by highlighting how perceptions of those working in social care in the two fields are embedded within existing segmented approaches. The study responds to Putnam’s (2011) suggestion that perceptions of professionals working on disability and older people’s programmes are important to the successful integration/alignment of these separate programmes and that there has been little investigation of those perceptions. The study also highlights how the lack of a shared understanding of what disability is across the two fields acts as a barrier to closer working.

11.5 Implications for Scholarship

A number of implications for scholarship are implicit in the above, which I summarise here.

The study points to the need for more exploration of subjective experiences of later life, for more theoretical engagement with disablement processes in later life, and for more nuanced theoretical understandings of the lifecourse (as applied to older age). It also suggests the need for more exploration of how disabled elders create meaning in life and of the implications for scholarship.

There is a particular need for research into the experiences of the AwD group, and their heterogeneity suggests that there is scope for revealing a wide spectrum of experience. More understanding of social constructions of disability in older age is also needed, because a key insight of social models of disability and critical disability studies - that disability is not just a personal, individual issue and that it is in part, at least, socially created – has yet to be applied to any extent to the experience of disability in older age. Furthermore, little is known about how the DwA experience (and indeed the AWD experience) compares with the experience of disabled people generally.

This study shows how the transitions experienced in older age are more complex and various than those that have to-date received most attention in scholarship and it highlights agentic responses by older people to them and socially-constructed aspects of them. It supports suggestions of the need for the emergence of counter narratives of ageing that transcend notions of ‘decline’ and ‘success’ or ‘third’ and ‘fourth’ ages. Specifically, it suggests the need for counter-narratives that recognise both the challenges that disablement processes represent for a sense of life as meaningful and the ways that disabled elders respond to those challenges. This requires a realistic engagement with the nature of humanity, including its limitations, but not *only* its limitations. It requires a counter-narrative of ageing and the lifecourse that can integrate disablement processes as a ‘normal’ part of life, and that can recognise both the challenges of disablement processes in older age *and* the ongoing efforts of disabled elders to perceive value and meaning in their lives. As I suggested in the Introduction, this requires critical responses to orthodoxies in both disability studies and social gerontology.

Overall, the extent to which constructions of ageing and of disability, and the social devaluation of each, are intertwined and linked to fears of human vulnerability means that these issues would benefit from approaches that address them across the life span for both disabled people generally and for disabled older people (AwD and DwA). Thus, in a fundamental way, the study challenges the degree of separation between the fields of ageing and disability. At the least, more scholarship that links them or attempts to cross boundaries is needed.

I suggest that there is a need for bridging research linked to development of social policy, as demographic ageing will increase pressure on policy-makers to make changes, and to cut costs, and such scholarship might help inform directions taken.

Finally, there are a few areas that this study's findings raise that I have not been able to explore to any great extent though they merit further exploration. They include the role of gender issues, class and material resources in later life disablement processes. Furthermore, positive experiences of newly engaging in communal activities that some participants had (including with others experiencing similar impairments and challenges) suggest a positive aspect of later-life with impairment (DwA and AwD groups) that has not been explored in scholarship. A useful contribution would involve delineating the factors that make this possible for some people and not others.

11.6 The Study's Contribution to Policy and Recommendations

In this section I draw together contributions to policy that I referred to in previous Chapters and I make recommendations for policy-making. The key finding of this study - that disabled older people are engaged in a process of seeking to have lives they perceived as meaningful – suggests a challenge for governments and communities to help them meet this need. That, and the levels of suffering and disruption that the study evidences they experience (due to disablement processes simultaneously with losses of intimates), challenges us to respond. I suggest that the findings represent a challenge to develop a more communal approach that emphasises the social not the biological, and that can keep disabled older people connected and included in as many aspects of life as possible. Not least, it means that public policies need to aim to ensure that all the participation opportunities that communities offer are inclusive of older disabled people.

I pointed to anomalies and inconsistences in the provision of social care in **Chapters 4** and **6**, especially, and also in other Chapters. The study confirms that disability policies are informed by social models and human rights approaches, and that they emphasise social needs, participation and user-direction, while policies on ageing are aligned to narrower medicalised approaches. Given that loss of intimates is common to older age, and a key aspect of the experience of disability (for DwA and AwD groups), this lack of emphasis on the social is somewhat paradoxical.

Public services played a major role in the lives of many participants as did community centres (for older people and disabled people) and the nature of those services was important as were the relationships they involved. But people experiencing similar levels of impairment and with similar aspirations for their lives could experience very different levels of support from public services and they could have very different experiences depending on whether they had social and financial resources. People within older people's services, in particular, experienced social-care services that lacked a focus on social engagement, and they often regretted their consequent confinement and inability to shape their lives (especially if they lacked resources to compensate); a few were accommodated in senior housing that was inaccessible and incapable of meeting needs that changed over time.

By contrast, public policy models that operated within disability services that were supportive and facilitative of choice-making, participation and connection with others could help translate aspirations for a meaningful life into more of a reality, and community organisations could also help with this. Thus, my findings suggest that public policies on ageing would serve all disabled older people better if (like disability services at least as experienced by *some* participants) they also emphasised these aspects, as well as aiming to make physical environments fully accessible. Public approaches, need, therefore, to have a broad approach (encompassing community, environmental, housing, cultural and other aspects of public administration).

Local disability and older people’s centres operated as a vital outlet for many participants. Participants valued kindness of staff, provision of accessible transport and attractive surroundings, activities involving challenge and learning, and social opportunities that connected them to others and that enabled them to contribute. Thus, my findings suggest that, as well as socialising, care centres should aim to provide opportunities for self-development and contribution – not just passing time. What was provided in some care centres, especially for older people, was experienced as unattractive/unsupportive, and some older people’s centres could benefit from norms that underpin disability services.

The current separate frameworks on disability and ageing appear to contribute to a series of anomalies and to affect different people in different ways. For example, the separation benefitted some people who remained within disability services after age 65 (whether for home supports or attendance at disability centres). Some of these participants from the AwD group would have experienced a diminution in services had they been transferred to older people’s services at age 65, and amongst them were participants who had lived the most marginalised lives. This points to the fact that attempts to integrate or align the two sectors could result in diminution for some *unless* service levels are increased for all disabled elders and are brought more in line with the aims that underlie disability services. These, I suggest, are important considerations. They point to some of the challenges associated with greater integration. I echo the concerns of some participants working in the field that change or integration might be undertaken to save money rather than to effect real improvements.

As already mentioned, above, this study adds to an emerging body of knowledge about what some of the barriers to bridging the two fields might be by highlighting the issue of professional investment in age-segmented approaches. These issues, I suggest, need to be articulated and addressed before attempts at change or integration are attempted. My review of international experience (**Chapter 4**) suggests that problems arise both because of artificial distinctions based on chronological age *and* from applying approaches associated with disability activism to the social care of older people without sufficient scrutiny of all the issues. Thus, alignment or integration of disability and older people’s frameworks is complex, is sometimes undertaken concurrently with funding reductions, and mistakes are made. This highlights the need for more scrutiny of all issues involved both by researchers and policy-makers before embarking on change, as well as the need for more research linked to policy-making that bridges the two fields.

Currently in Ireland the separate frameworks on disability and ageing seem to result in neither sector learning from the other - sometimes reproducing ablest or ageist notions, respectively. Implications include the need for more interchange and learning, involving interrogation of their respective definitions, informing philosophies and concepts and resulting practices, including their use of technology. These exchanges could benefit all disabled older people, and they are vital for members of the AwD group who require an active interchange between the two sectors. However, the concurrent (separate) proposals for personalised budgets and proposals for a statutory scheme for homecare in Ireland suggest that the bifurcated approach to ‘disability’ and ‘ageing’ continues and may be copper-fastened.

As I suggested in **Chapter 4**, in Irish public policy on ageing (which appears to mirror the position in other countries), the focus on active or positive ageing means that there is currently a gap in the framing of strategies for older disabled people (DwA and AwD). The *National Positive Ageing Strategy* (the implementation of which is long-delayed) does not focus on values or intended outcomes for disabled older people. An implication is that more work needs to be done to articulate what ‘positive’ ageing means for older disabled people and what supports and services are required, what barriers need to be removed, and what types of relationships and communities we need to create to foster integration. This is an issue for those promoting international active ageing approaches as well as for national governments.

Furthermore, policies for ageing populations need a specific focus on the situation of people lacking financial or social resources. There also needs to be a particular focus on the AwD group and for anyone experiencing disability over a long time, because of the cumulative disadvantage involved. Also, without a specific policy focus, their position from age 65 may continue to be worked out in ways that are not transparent or consistent.

Finally, as a prerequisite to change, I suggest that ways are needed of understanding disability that are shared across scholarship, policy and practice in the fields of disability and ageing. This study suggests that a biopsychosocial understanding is compatible with how disabled older people experienced disability.

Summary of Policy Recommendations

For policy-making at **an international** level:

- Those working on ageing should
    - consider adopting a biopsychosocial understanding of disability (as applied to DwA and AwD) and promote awareness amongst stakeholders of how this applies; and
    - develop the active ageing framework such that it becomes more informed by disabled older people (AwD and DwA) and specify actions that promote active ageing and inclusion for these groups;
- Those working on both ageing and disability should develop an active interchange between developments on active ageing and international approaches on disability and develop an integrated approach to the AwD group and the DwA group.

For policy-making at a **national** level:

Policy for both older people and disability should:

- Clarify how disability in older age is understood; consider adopting a biopsychosocial understanding of disability and promote awareness amongst stakeholders in disability and older people's sectors;
- Develop the country's care centres and other community venues to provide quality services to disabled older people (while they should not be the only opportunities for them), including attractive surroundings, accessible transport, choice and quality in activity opportunities and social opportunities;
- Establish structures to facilitate active exchanges between respective knowledge, technologies and skills within the disability and older people's sector, aiming to bring older people's services more in line with the aims that underlie disability services;
- Develop a focus within policies on disability and ageing for the AwD group and for anyone experiencing disability over a long time;
- Engage in scrutiny of all issues involved before embarking on change (including underlying assumptions and philosophies and investment of staff in existing age-segmented approaches) and engage in more research bridging the two fields.

Policy for older people should:

- Develop a greater emphasis on meeting the social and emotional needs of disabled older people and on supporting their efforts to enhance and find meaning in their lives; specifically, policies and services should aim to support the exercise of choice, continued participation in all aspects of community life, and to make physical environments fully accessible;

- Consult with disabled elders to articulate what it means for *all* older disabled people to age positively and extend the *National Positive Ageing Strategy* accordingly; implement any resulting strategy.

11.7 Concluding Remarks

The key finding of this study that disabled older people are engaged in a process of seeking to have lives they perceived as meaningful represents a challenge for governments and societies. The fact that the emphasis on the social, that informs theorising, models and policy-frameworks on disability, is shown to be just as valuable for older disabled people as it is for disabled people generally represents another challenge. Finally, that the social devaluation of ageing and disability are intertwined points to the need for more unified and universal approaches to disability. This requires a reorientation in general thinking about disability and recognition of how it is an issue for all ages.

I find myself coming back to participants' accounts of using trolleys to lean on in super-markets (leaving rollators outside) or of others with rollators struggling to get seated before a bus-driver drives away. Given the prevalence of disability in older age, why, I wonder, are such everyday adaptations and challenges not more known, 'normal' and accommodated? The answer, I suggest, is associated with a culture where 'aging is shrouded in denial or shame' (Cruikshank 2003:7) and where similar underlying fears result in distancing from older people *and* disabled people (Irwin 1999). Instead, lives would be better if societies were more accepting of disability as a normal part of life, not some kind of individual failure, and if all older people were recognised as still involved in both challenge and growth, and specifically in seeking to live lives that they perceive as meaningful.

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Appendix A: Census Questionnaire 2011, 2016

The census questionnaire for Censuses 2011 and 2016 contained two questions relating to disability (16 and 17). Anyone who responded ‘yes’ to any of seven categories in question 16 on long-lasting conditions **or** ‘yes’ to any of the four categories in question 17 on difficulties is categorised as disabled (Central Statistics Office 2012a).

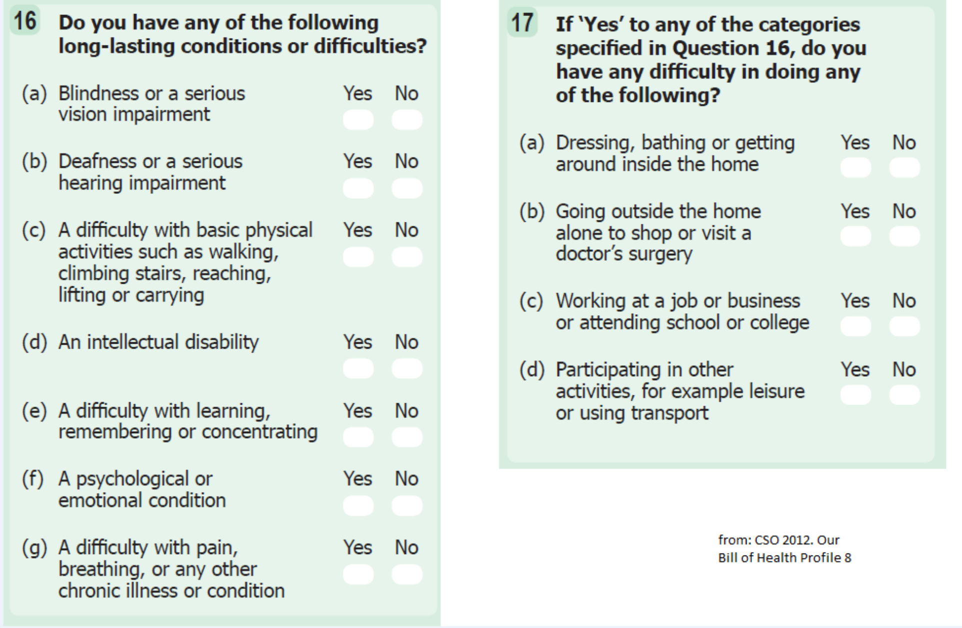
Question 16 asked about the existence of the following long-lasting conditions:

- blindness or a serious vision impairment,
- deafness or a severe hearing impairment,
- a difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying,
- an intellectual disability,
- a difficulty with learning, remembering or concentrating,
- a psychological or emotional condition, and
- a difficulty with pain, breathing, or any other chronic illness or condition.

If a person answered ‘yes’ to any of the parts of question 16, they were asked to answer question 17 which asked about a difficulty doing any of the following:

- dressing, bathing or getting around inside the home;
- going outside the home alone to shop or visit a doctor’s surgery;
- working at a job or business or attending school or college;
- participating in other activities, such as leisure or using transport.

Individuals were classified as having a disability if they answered ‘yes’ to any part of the above two questions, including if they ticked ‘yes’ to any of the parts of question 17 even though they may not have ticked ‘yes’ to any of the parts of question 16 (Central Statistics Office 2012a, Appendix 2).



16 Do you have any of the following long-lasting conditions or difficulties?

		Yes	No
(a)	Blindness or a serious vision impairment	☐	☐
(b)	Deafness or a serious hearing impairment	☐	☐
(c)	A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying	☐	☐
(d)	An intellectual disability	☐	☐
(e)	A difficulty with learning, remembering or concentrating	☐	☐
(f)	A psychological or emotional condition	☐	☐
(g)	A difficulty with pain, breathing, or any other chronic illness or condition	☐	☐

17 If ‘Yes’ to any of the categories specified in Question 16, do you have any difficulty in doing any of the following?

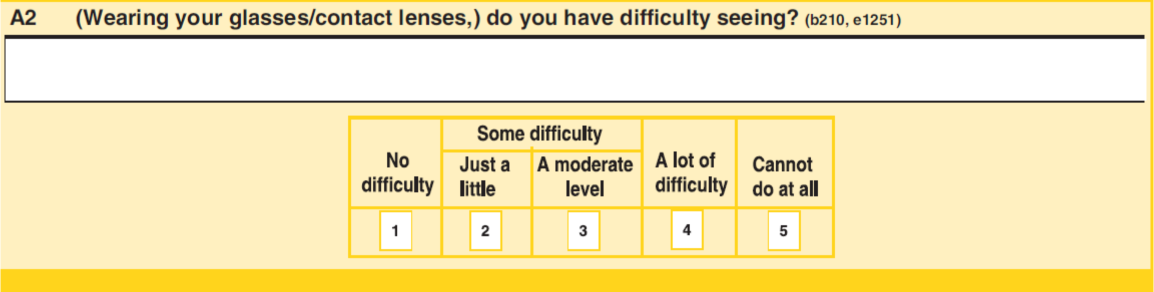
		Yes	No
(a)	Dressing, bathing or getting around inside the home	☐	☐
(b)	Going outside the home alone to shop or visit a doctor’s surgery	☐	☐
(c)	Working at a job or business or attending school or college	☐	☐
(d)	Participating in other activities, for example leisure or using transport	☐	☐

from: CSO 2012. Our Bill of Health Profile 8

Appendix B: Sample Severity-Scale, NDS Questionnaire

Example of filter questions relating to disability severity from National Disability Survey Questionnaire adapted for use in interviews for this study:

Section A – Seeing



A2 **(Wearing your glasses/contact lenses,) do you have difficulty seeing?** (b210, e1251)

No difficulty	Some difficulty		A lot of difficulty	Cannot do at all
	Just a little	A moderate level		
1	2	3	4	5

Central Statistics Office 2008, Appendix B

Appendix C: Census Questions Adapted to include Severity Scale

Census 2011 Questions 16 and 17 as Adapted for use at the end of each interview

Do you have any of the following long-standing conditions or difficulties			
1.	Blindness or a serious vision impairment	Yes ☐	No ☐
2.	Deafness or a serious hearing impairment	Yes ☐	No ☐
3.	A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying	Yes ☐	No ☐
4.	An intellectual disability	Yes ☐	No ☐
5	A difficulty with learning, remembering or concentrating	Yes ☐	No ☐
6.	A psychological or emotional condition	Yes ☐	No ☐
7.	A difficulty with pain, breathing, or any other chronic illness or condition	Yes ☐	No ☐

Level of difficulty (if wearing glasses or hearing aids – in the case of vision/hearing impairment)				
No Difficulty	Some Difficulty		A lot of difficulty	Cannot do at all
	Just a little	A moderate level		

If 'Yes' to any of the categories specified in questions the previous do you have any difficulty doing the following?			
1.	Dressing, bathing or getting around inside the home	Yes ☐	No ☐

Level of difficulty				
No Difficulty	Some difficulty		A lot of difficulty	Cannot do at all
	Just a little	A moderate level		

2.	**Going outside the home alone to shop or visit a doctor’s surgery**	**Yes** ☐	**No** ☐

Level of difficulty				
No difficulty	**Some Difficulty**		**A lot of difficulty**	**Cannot do at all**
	Just a little	**A moderate level**		

3.	**Working at a job or business or attending school or college**	**Yes** ☐	**No** ☐

Level of Difficulty				
No Difficulty	**Some Difficulty**		**A lot of difficulty**	**Cannot do at all**
	Just a little	**A moderate level**		

4.	**Participating in other activities, for example, leisure or using transport**	**Yes** ☐	**No** ☐

Level of Difficulty				
No Difficulty	**Some Difficulty**		**A lot of difficulty**	**Cannot do at all**
	Just a little	**A moderate level**		

Based on:
Central Statistics Office 2012a
Central Statistics Office 2008

Appendix D: Information Sheets – Older Participants

Sample 1 – Information Sheet Used for Group 1 (disability with ageing) – includes Consent Form

Information for Potential Research Participants

My name is Ann Leahy. I am a post-graduate researcher at the Department of Sociology, Maynooth University.

I am inviting you to participate in a piece of research. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and, if you wish, discuss it with family or friends. Please ask if there is anything that is not clear or if you would like more information.

This information sheet explains the nature of the study, and what we will be asking you to do in the interview. It also explains how your interview will be used.

About the research

The purpose of this research is to obtain in-depth information on how people experience ageing with and without long-standing conditions or difficulties (due to illness, impairment or disability) which have a noticeable impact on their lives. About 50 people will be interviewed for this research.

The research is exploring, in particular, what it is like to experience impairment or disability with ageing, what sustains people and what hinders them in continuing to lead meaningful lives. Participants will be asked to talk about their experiences, to tell their stories of daily life in one-to-one interviews with me.

The research is being conducted in the Department of Sociology at Maynooth University. The interviews gathered in this research are being carried out as part of my doctoral research and will become part of an archive available to researchers interested in how people age in Ireland.

My supervisor is Dr Jane Gray, Senior Lecturer, Department of Sociology at Maynooth University**.**

Why Have You been Asked to Participate?

Amongst the people that I am asking to take part in this study are people who are aged over 65 and who are experiencing long-standing physical or sensory conditions or difficulties (due to illness, impairment or disability) which are having a noticeable impact on their lives.

Do I have to take part?

No – taking part is voluntary. It is up to you to decide whether or not to take part. If you decide not to take part you do not have to give a reason, nobody will be upset and there will be absolutely no impact on any services you may currently receive.

If you do decide to take part I will ask you to sign a consent form before the interview starts and give you a copy to keep. If you decide to take part, and then change your mind, you are still free to withdraw at any time even after you have signed the consent form.

About the interview

I will arrange to meet you for a conversation or interview about your life and about your experience of illness, impairment or disability. Because we are interested in hearing about your life events, there is no set time limit within which the interview will be carried out, but we anticipate that it will not last longer than about one hour. The interviews can be arranged to take place wherever is most convenient for you. I can visit you at home if you wish.

Possible risks/benefits of taking part

The information you give is intended to help us find out what life is like from the perspective of older people. This study involves talking to me about your experiences. There should be no risk to your physical health in taking part, but some people may find it upsetting to talk about their feelings or about coping with challenges. If you do begin to find that talking about your experience upsetting we will stop the interview until you feel better, or stop it altogether if that is what you would prefer.

In addition, some people sometimes find it helpful to have the opportunity to talk about their experiences and feelings in studies similar to this.

How we will use and safeguard your information

With your permission, the interview will be audio-recorded – but you can ask that the recording be stopped at any time. Afterwards it will be transcribed. Both the recording and transcription will be stored on an encrypted computer. Your name and other information that might identify you will be removed from all written information such as transcripts of interviews. The final results of this study will be known in a few years' time when all interviews have been obtained and analysed. If you wish, I will let you know the results when they are available. Results will be reported in articles, books or meetings so that the best possible use can be made from the research, but you will not be identifiable in any way.

Again, with your permission, once all the interviews are completed, the transcripts will be placed in an archive, where other researchers may consult them. But before your interviews are deposited in the archive, your name will have been removed, and your comments will not be attributable to you. All other information that you have provided will be destroyed.

I may use quotations from interviews in documents and publications about the
study and these also will be made anonymous so that you cannot be identified.
None of the information that you give will be fed back to anyone who may be involved in making any services available to you.

It must also be recognized that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances Maynooth University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

Who is funding the research?
This study is being funded by the Irish Research Council,

Who has reviewed the study?
The study has been approved by the Maynooth University Ethics Committee.

What happens now?
Thank you for considering taking part in this research. I will follow up with you and give you the chance to ask any questions that you have and discuss whether you would like to take part. Or you can contact me by phone or email.

Once again, it is important for you to know that your participation in the research is entirely voluntary. You may withdraw your consent to participate at any time, without obligation and without giving a reason.

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Auxilia Building, North Campus,
Maynooth University,
Maynooth
Co. Kildare
tel: 01 7083659 (Department of Sociology, Maynooth University)
email: ann.leahy.2014@mumail.ie

Project Title: Ageing and Physical and Sensory Disability.
Researcher: Ann Leahy **Supervisor:** Dr Jane Gray

Material gathered during this research will be treated as confidential and securely stored on an encrypted computer.

Please answer each statement below concerning the collection of the research data.

1.	**I have read and understood the information sheet**	**Yes** ☐ **No** ☐
2.	**I have been given the opportunity to ask questions about the research**	**Yes** ☐ **No** ☐
3.	**I have had my questions answered satisfactorily**	**Yes** ☐ **No** ☐
4.	**I understand that I can withdraw from the study at any time without having to give a reason**	**Yes** ☐ **No** ☐
5.	**I agree to the interview being audiotaped, its contents transcribed and to its contents being used for research purpose**	**Yes** ☐ **No** ☐
6.	**I agree to the transcripts being archived and used by other bona fide researchers provided that my name has been removed and that my comments have not been attributed to me**	**Yes** ☐ **No** ☐

Name (printed)____

Signature____

Date______________________________

About 50 people are taking part in this research project. Your contribution is immensely valuable. Feel free to contact us is you have any further questions

Ann Leahy and Dr Jane Gray may be contacted at:

Department of Sociology
Auxilia Building, North Campus,
Maynooth University,
Maynooth
Co. Kildare

tel: 01 7083659 email: sociology.department@nuim.ie

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Sample 2 – Information Sheet (First page only – in other respects as per sample 1) used with Group 2 (Ageing with disability)

Information for Potential Research Participants

My name is Ann Leahy. I am a post-graduate researcher at the Department of Sociology, Maynooth University.

I am inviting you to participate in a piece of research. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and, if you wish, discuss it with family or friends. Please ask if there is anything that is not clear or if you would like more information.

This information sheet explains the nature of the study, and what we will be asking you to do in the interview. It also explains how your interview will be used.

About the research

The purpose of this research is to obtain in-depth information on how people experience ageing with and without long-standing conditions or difficulties (due to disability, impairment or illness) which have a noticeable impact on their lives. About 50 people will be interviewed for this research.

The research is exploring, in particular, what it is like to age with the experience of lifelong disability or impairment, what sustains people and what hinders them in continuing to lead meaningful lives. Participants will be asked to talk about their experiences, to tell their stories of daily life in one-to-one interviews with me.

The research is being conducted in the Department of Sociology at Maynooth University. The interviews gathered in this research are being carried out as part of my doctoral research and will become part of an archive available to researchers interested in how people age in Ireland.

My supervisor is Dr Jane Gray, Senior Lecturer, Department of Sociology at Maynooth University.

Why Have You been Asked to Participate?

Amongst the people that I am asking to take part in this study are people:

- who are aged 65 or over;
- who have experienced physical or sensory conditions or difficulties (due to disability, impairment or illness) which have had a noticeable impact on their lives for about 20 years before age 65.

Sample 3 – Information Sheet (First page only– in other respects as per sample 1) used with Group 2 (Ageing without disability)

Information for Potential Research Participants

My name is Ann Leahy. I am a post-graduate researcher at the Department of Sociology, Maynooth University.

I am inviting you to participate in a piece of research. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and, if you wish, discuss it with family or friends. Please ask if there is anything that is not clear or if you would like more information.

This information sheet explains the nature of the study, and what we will be asking you to do in the interview. It also explains how your interview will be used.

About the research

The purpose of this research is to obtain in-depth information on how people experience ageing with and without long-standing conditions or difficulties (due to illness, impairment or disability) which have a noticeable impact on their lives. About 50 people will be interviewed for this research.

The research is exploring, in particular, what it is like to experience impairment or disability with ageing, what sustains people and what hinders them in continuing to lead meaningful lives. Participants will be asked to talk about their experiences, to tell their stories of daily life in one-to-one interviews with me.

The research is being conducted in the Department of Sociology at Maynooth University. The interviews gathered in this research are being carried out as part of my doctoral research and will become part of an archive available to researchers interested in how people age in Ireland.

My supervisor is Dr Jane Gray, Senior Lecturer, Department of Sociology at Maynooth University**.**

Why Have You been Asked to Participate?

Amongst the people that I am asking to take part in this study are people who are aged over 65 who and are not experiencing long-standing physical or sensory conditions or difficulties.

Appendix E: Information for Interviews with Policy-makers, service-providers and those involved in advocacy

Orienting Topics, Interview Guide and Information Sheet

<u>Orienting Topics – to be shared in advance</u>

- Your role in policy-making/service provision/advocacy for older people or disabled people.
- How the services/programmes of your organisation support older disabled people – for example, how the services are accessed and experienced.
- OR how your members/constituency access and experience services (especially health and social care or long-term care) when they need them.
- Differences in approaches to services for disabled people and older people.
- Lessons from one sector/area that could be applied in the other.

<u>Interview Questions – to be used flexibly</u>

- What is your role in policy-making/service/programme provision/advocacy for older people/ disabled people?
- How does your work support older people [or] disabled people?
- What does the term ‘disability’ mean to you? What about the term ‘disabled older person’?
- **[for people from disability services]** Does your service support/include life-long disabled people in older age (say, after 65)? If so, how?
- **[for people from ageing services]** How does your service ascertain which older people should receive services or be involved in your programme? Is there an age-threshold for receipt of services? What about people who are disabled before age 65?
- **[for people from NGOs]** how do your members/constituency access and experience services (especially social care or long-term care) when they need them?
- Describe how service users access and experience the provision of social care services in your field.[76]
- Are there lessons/good practice in disability or ageing services that could be applied in the other sector?
- Do you think that there are advantages/disadvantages in greater integration of the two services or the two sectors?
- What are the main gaps in services as you perceive them for the people you serve and what should be done to address them?

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[76] For example, person-centred? Rights-based? Empowering? Discretionary? Administratively-led?

Participant Information Sheet and Consent Form: Policy-makers, Service Providers etc

Thank you for agreeing to participate in this study. About 50 people will be interviewed for this research. Your contribution is immensely valuable. This information sheet explains the nature of the study, and what we will be asking you to do in the interview. It also explains how your interview will be used.

About the research

The purpose of this research is to obtain in-depth information on how people experience ageing with and without disability. The main focus is the experience of disability in older age, exploring in particular how people negotiate disability as they age, what sustains them and what hinders them in continuing to lead meaningful lives.

The research is also intended to inform policy-making and service provision and thus will also explore the public policy context for both ageing and for disability and the distinctions made in service provision and in a range of institutional practices between people experiencing life-long or early-onset disability, on the one hand, and disability with ageing, on the other.

The research will explore these issues with a number of different groups.

One group is made up of people who are familiar with public policy on ageing and disability or who are engaged in (or have been engaged in) service provision to disabled people or older people.

Other groups include:

- people who experience disability as they age;
- people who are ageing with life-long or early-onset disability, and
- people who are ageing without disability.

The interviews gathered in this research are being carried out as part of Ann Leahy's doctoral research and will become part of an archive available to bona fide researchers interested in how people age in Ireland.

The research is being conducted in the Department of Sociology at Maynooth University.

The Researcher is Ann Leahy who is a doctoral candidate responsible for carrying out this research. Her supervisor is Dr Jane Gray, Senior Lecturer, Department of Sociology at Maynooth University.

Ann Leahy and Dr Jane Gray may be contacted at:

Department of Sociology
Auxilia Building, North Campus,
Maynooth University,
Maynooth
Co. Kildare

tel: 01 7083659 email: sociology.department@nuim.ie

About the interview
The Researcher, Ann Leahy, will meet you in your office to interview you about your experience of public policy and/or service provision in the fields of disability and/or ageing. We anticipate that this interview will last approximately one hour.

How we will use and safeguard your information
With your permission, the interview will be recorded but your contribution will be anonymised and kept confidential. Afterwards it will be transcribed. Both the recording and transcription will be stored on an encrypted computer.

It must also be recognized that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances Maynooth University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

Again, with your permission, once all the interviews are completed, the transcripts will be deposited in an archive, where other bona fide researchers may consult them. Before your interviews are deposited in the archive, your name will be removed, and your comments will not be attributable to you. All other information that you have provided will be destroyed.

Once again, we thank you for your participation. However, it is important for you to know that your participation in the research is entirely voluntary. You may withdraw your consent to participate at any time up to publication without obligation and without giving a reason.

Having read this information sheet, please read and sign the consent form.

Consent Form
Project Title: Ageing and Disability
Researcher: Ann Leahy **Supervisor:** Dr Jane Gray, Senior Lecturer

Material gathered during this research will be treated as confidential and securely stored on an encrypted computer.

Please answer each statement below concerning the collection of the research data.

1.	**I have read and understood the information sheet**	**Yes** ☐ **No** ☐
2.	**I have been given the opportunity to ask questions about the research**	**Yes** ☐ **No** ☐
3.	**I have had my questions answered satisfactorily**	**Yes** ☐ **No** ☐
4.	**I understand that I can withdraw from the study at any time (up to publication) without having to give a reason**	**Yes** ☐ **No** ☐
5.	**I agree to the interview being audiotaped, its contents transcribed and to its contents being used for research purposes**	**Yes** ☐ **No** ☐
6.	**I agree to the transcripts being archived and used by other bona fide researchers provided that my name has been removed and that my comments have not been attributed to me**	**Yes** ☐ **No** ☐

Name (printed)____

Signature____**Date**____________

About 50 people are taking part in this research project. Your contribution is immensely valuable. Feel free to contact us is you have any further questions

Ann Leahy and Dr Jane Gray may be contacted at:
Department of Sociology, Auxilia Building, Maynooth University, Maynooth, Co. Kildare
tel: 01 7083659 email: sociology.department@nuim.ie

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the National University of Ireland Maynooth Ethics Committee at research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Appendix F: Profile of Participants

DwA, Disability with Ageing: Participants, Key Characteristics

	Pseudonym	Sex	Age	Decade of Onset	Living Arrangements	Family Status	Location	SES	Dis Type 1	Dis Type 2 (if any)	Timing of Onset. Further Impairment Details	Severity (self-report)
1	Angelina	F	65	50s	Alone (with Warden)	S	City	M	Mobility	Pain/ breathing/ other	Accident at 55 caused back problems. Many operations since. Pain. Uses rollator.	5
2	Annette	F	84	80s	with Spouse and others	M	Village	L	Mobility	Pain/ breathing/ other	Sudden onset of several conditions including heart disease in 80s. Uses a stick and rollator.	2
3	Carmel	F	69	60s	Alone	S	Rural	L	Mobility	Memory	Health issues from late 50s leading to both legs amputated in 60s. Uses wheelchair.	5
4	Colin	M	88	80s	with Spouse	M	City	H	Vision	Memory	Macular degeneration onset in 80s.	4
5	Edward	M	68	50s	Alone	Sep/ Divorced	Village	M	Mobility	Pain/ breathing/ other	Muscular Dystrophy diagnosis at age 50. Soon afterwards started using a wheelchair	5
6	Finbar	M	73	50s	with Spouse	M	Town	M	Mobility	None	Accident at age 58 and sustained head injury. Uses rollator and wheelchair.	2
7	Francis	M	76	50s	with Spouse	M	Rural	M	Mobility	Hearing	Stroke at age 58, minor ones since; also broke his hip and subsequently his ankle. Used rollator, now wheelchair.	5
8	Gloria	F	80	70s	with Spouse and carer	M	City	H	Mobility	Pain/ breathing/ other	Gradual mobility issues from 70s. A fall 2.5 years ago resulted in hip fracture. Pain and other issues since	4

9	James	M	83	80s	Alone	W	City	H	Mobility	Hearing	Stroke and other health issues in 80s. Uses rollator and wheelchair.	5
10	Joan	F	86	70s	Alone with others nearby	W	Rural	M	Mobility	Pain/ breathing/ other	Gradual onset of mobility issues rom 50s on, but especially from late 70s. Back pain. Uses rollator.	3
11	Josephine	F	78	70s	with Adult child	W	Rural	H	Vision	Mobility	Slight stroke in her early 70s. Glaucoma onset in recent years. Uses stick.	3
12	Julie	F	80	70s	with Spouse	M	City	M	Mobility	None	Gradual onset of arthritis, knee problems and breathlessness due to heart disease. Has also had several bouts of cancer	3
13	June	F	82	70s	Alone (with Warden)	W	City	L	Mobility	Vision	Gradual onset since retirement especially in 70s. Uses rollator and scooter. Vision impairment now.	4
14	Kathleen	F	85	60s	Alone	S	City	M	Mobility	None	Gradual onset since retirement	3
15	Maggie	F	78	70s	with adult child	W	City	L	Mobility	Not known	Both legs amputated in 70s due to illness. Wheelchair user.	Not Known
16	May	F	67	40s	Alone	S	City	M	Psychological	Mobility	Mobility issues due to circulation and a back problem. Pain. Mental health issues in adulthood	3
17	Paul	M	69	50s	with Spouse	M	City	H	Mobility	Memory	Had a stroke in late 50s; partial paralysis of left leg. Balance issues. Uses rollator and wheelchair sometimes.	2
18	Phil	M	74	60s	with Spouse	M	City	L	Mobility	Pain/ breathing/ other	Both legs amputated in 60s due to diabetes. Uses wheelchair.	4
19	Rory	M	68	60s	with Spouse and adult child	M	City	M	Mobility	Vision	Two strokes in his 60s. Uses rollator and wheelchair. Balance issues.	4

20	Seamus	M	78	40s	Alone	Sep/Divorced	Town	H	Hearing	Mobility	Noticed hearing loss from late 40s. Used a hearing aid from 50s. How has ‘dead’ ear.	1
21	Stephen	M	88	80s	Alone	W	City	L	Mobility	Pain/ breathing/ other	Gradual onset in recent decade. Uses rollator.	3
22	Timmy	M	78	50s	with Adult child/children	Sep/Divorced	City	H	Pain /breathing/ other	Hearing	Noticed hearing loss in his 50s.Wearing hearing aids now for about 6 years. Also has balance issues and an underlying cancer diagnosis	2
23	Una	F	65	50s	with Spouse and adult child	M	Village	M	Mobility	Speech	Multiple Sclerosis onset around 50. Uses a wheelchair	5
24	William	M	70	50s	with Spouse and adult child	M	Village	L	Mobility	None	Had a stroke at age 54 which paralysed his left side. Walks with a stick and has no use of left hand.	3

Notes:

SES: Socio-economic status: M= Middle; L= Low; H=High. Calculated using occupational status categorisation used by the Central Statistics Office (CSO) of Ireland (Central Statistical Office 2012c; 2012d) and grouping into three categories of high, middle and low SES (adopting the approach of Timonen *et al.* 2013).

Family Status: M= married; S=single; Sep/divorced= separated or divorced

Severity scale from a five-point scale (of ‘no difficulty=1’ to ‘a lot of difficulty=4’ and ‘cannot do at all=5’) as used in the National Disability Survey 2006 (CSO 2008) and as applied to the activity limitations enquired of in Census question 17. **Note** I did not take into account responses to one of the questions – about working or attending school or college - as most participants did not think this was relevant to them.

‘Not Known’ relates to one participant whose interview ended early before answering the Census categorisation question (and who died before the interview could be rescheduled).

Finally, two participants opted for 'other' relative to their primary disability: (1) one opted to describe hers as a psychological condition and mobility as a secondary condition, and (2) one DwA participant reported hearing as a secondary condition and an underlying bout of cancer as his first.

AwD, Ageing with Disability: Participants, Key Characteristics

	Pseudonym	Sex	Age	Decade of Onset	Living Arrangements	Family Status	Location	SES	Dis Type 1	Dis Type 2 (if any)	Timing of Onset; Further Impairment Details	Severity (self-repor)
1	Alice	F	72	40s	Alone	Sep/Divorced	City	L	Mobility	None	Had health issues all her life. Sudden onset of back problems in 40s. Uses rollator.	4
2	April	F	65	0-10	Alone	W	City	L	Mobility	Pain/ breathing/ other	Polio diagnosed at 3. Limped and wore leg-brace and stacked shoe. Post polio syndrome from early 40s. Wheelchair user.	2
3	Babs	F	67	birth	Alone with 24-hr support	S	Town	L	Mobility	Pain/breathing / other	Born with Cerebral palsy. Wheelchair user.	5
4	Blanad	F	60	30s	with Spouse	M	Rural	H	Mobility	Pain/breathing / other	Parkinson’s disease from age 30. Sometimes uses stick.	5
5	David	M	72	birth	Alone	W	City	M	Vision	None	Born with visual impairment.	1
6	Desmond	M	72	birth	with Spouse	M	City	M	Vision	Hearing	Born with visual impairment.	1
7	Eileen	F	66	birth	Alone with Support	S	City	L	Mobility	Hearing	Born with Cerebral palsy. Series of other impairments. Wheelchair user.	5
8	Hazel	F	80	30s	Alone with carers overnight	W	Village	H	Vision	Hearing	Visual impairment since accident in her 30s; more gradual onset of hearing impairment since.	5
9	Helen	F	68	10-20	Alone (with Warden)	S	City	M	Mobility	Pain/ breathing/ other	Accident, age 12 caused scoliosis. Health problems from 30s meant needing oxygen over-night. Also needs day-time oxygen now.	5

10	Janice	F	66	40s	with Spouse/Partner	Sep/Divorced	City	L	Mobility	Vision	Multiple sclerosis in early 40s. Uses rollator and scooter sometimes.	3
11	Len	M	69	10-20	with Spouse	M	Village	L	Mobility	None	Leg amputated due to accident in his teens. Wheelchair user since.	1
12	Liz	F	55	40s	with Adult child	S/D	City	M	Mobility	Vision	Stroke at age 42. No use of left hand. Walks with a stick (sometimes rollator/scooter/wheelchair)	4
13	Patricia	F	90	20s	Alone	S	City	M	Mobility	Hearing	Had a stroke in her early 20s. Affected her face and her walking (used stick). Further mobility issues gradually later. Uses rollator in the past 10 or 11 years.	3
14	Peggy	F	83	10-20	Alone with others nearby	S	Rural	M	Mobility	None	Polio onset at age 13. Walked with crutches until recent decades. Now uses wheelchair.	5
15	Sheila	F	61	30s	with Adult child	W	City	H	Mobility	None	Multiple sclerosis onset in her 30s. Wheelchair user.	5
16	Simon	M	66	birth	Alone	W	Town	M	Vision	None	Born with visual impairment.	4
17	Teresa	F	87	birth	Alone	S	Rural	L	Mobility	Vision	Born with spina bifida. Walked with crutches. Vision impairment in recent years. Now uses wheelchair.	5
18	Tony	M	83	0-10	Alone (with Warden)	S	City	L	Mobility	Pain/ breathing /other	Accident when a toddler caused lameness and short leg. Gradual disimprovement means uses rollator in recent decades.	3

Notes: For abbreviations, see notes with previous Table

ND, No Disability: Participants, Key Characteristics

Category	Pseudonym	Sex	Age	Living Arrangements	Marital Status	Location	SES	Dis Type 1	Dis Type 2 (if any)	Level of difficulty caused
1	Albert	M	78	Alone with others nearby	S	Village	H	Hearing	Pain/breathing/other	none
2	Betsy	F	78	Alone with others nearby	W	Rural	L	Memory	Hearing	none
3	Christine	F	81	Alone	W	City	H	Pain/breathing/other	Hearing	none
4	Jill	F	82	Alone	W	City	H	None	None	N/A
5	Maura	F	66	Alone	Sep/Divorced	Rural	M	Pain/breathing/other	None	none
6	Monica	F	72	Alone	W	Rural	L	Pain//breathing/other	None	none
7	Roz	F	77	Alone (with Warden)	W	City	M	None	None	N/A
8	Ruth	F	94	Alone with others nearby	W	City	M	None	None	N/A

Notes: For SES, see previous Table

Note: Even though some of these participants reported that they had conditions (like high blood pressure, asthma, or a prior episode of cancer), I categorised them as having ‘no disability’ if they reported that these caused them no difficulty. See Discussion in **Chapter 5**.

Appendix G: Samples of Initial Coding and Contributions to Category development

Example of Initial Coding Contributing to Development of sub-categories and main categories		
Extract from Stephen's Narrative But I do my own cooking and I was always dancing with [name of wife] , [name of wife] and I danced an awful lot together. Now we weren't ballroom dancers but we got around and she was a lovely dancer to dance with. And I miss that terrible. In fact I think it has affected me that I am not as mobile now since [name of wife] died two years ago, I am not mobile and I have collapsed in the street a few times. Now my son got me a walking frame.	**Examples of Initial Codes** Characterising self as independent. Contrasting life before and after. Experiencing loss of activity. Mixing bereavement and impairment. Describing impairment situation now. Experiencing repeated/ worsening events.	**Sub-categories (**and Main Categories**) to which these Codes Contributed** **Maintaining Everyday Activities** (Responding to Challenges) **Social/Familiar Factors** (Disabling Contexts) **Losing Activities and Participation Opportunities** (outcome of disabling bodies and disabling contexts) **Having a Heightened sense of Uncertainty** (outcome of disabling bodies)
Extract from Francis's narrative And that about sums up my little story. But the person, we'd no family. We're married forty-eight years this year. We have no children. That is a handicap at our stage definitely. My wife broke a bone in her back two and a half years ago.	**Examples of Initial Codes** Being childless. Lacking people to help. Describing impairment situation now. Experiencing Reduced circles. Experiencing the impairment/ illness of others.	**Increasing Perceptions of Disability from Lack of others or their Impairment** (Social/Familiar Factors, Disabling Contexts)

Extract from Teresa's narrative But anyway this evening came and this man come up to go with me and I asked [#name of brother who lived with Teresa], 'will you leave us up?' [to older people's centre] And he said, 'I suppose I have to.' [laughs] And that kind of thing puts you off, doesn't it? So he brought us up that night. And then there was other people, different ones joined in the club up here and they would bring me up – they'd call for me on their way up. I always nearly got up. Lord have mercy on him he died then and they knew there was nobody to bring me so I was always collected and brought. So that was grand. It really opened a new life for me and I went on holidays with them and everything	**Examples of Initial Codes** Experiencing negative inputs of Family. Grudging Support of family members. Fearing being a burden.? Experiencing community Support. Experiencing Reduced circles. Experiencing the impairment/ illness of others. Experiencing community Support. Valuing centres attended. Opening up of Life. Taking up new activities.	**Sub-categories (and Main Categories) to which these Codes Contributed** **Unsupportive Relationships Increasing Perceptions of Disability** (Social/Familial factors – disabling contexts) **Community Organising/Public Policies Helping with Lives that Make sense (**Responding to Challenges) **Social/Familiar Factors** (Disabling Contexts) **AwD 'Normalising' experiences** (socio-cultural meanings, Disabling Contexts) **Maintaining and Taking up new Activities** (Responding to Challenges)